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Brachial plexus birth injuries: community provider learning modules

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SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**BRACHIAL PLEXUS BIRTH INJURIES:
COMMUNITY PROVIDER LEARNING MODULES**

by

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requirements for the degree of
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DEDICATION

I would like to dedicate this work to my husband, Hull P. Maynard, III who has always been a loving, encouraging, and supportive partner for both our shared, and my individual passion, to optimize children and family's participation and engagement in meaningful occupations. I never would have been able to follow my passions without your love and encouragement. Much love always!

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I also want to thank my husband, sister and brother for their love and encouragement through my OTD adventure! Our phone calls through the pandemic and OTD journey provided me with the “grounding” I needed to put things in perspective along the way!

I also want to thank my dear friend and colleague Susan Morehouse, PT for her passion and commitment to working with children and families with Brachial Plexus Birth Injuries and collaborating with me on our different projects to better the lives of children with BPBIs. I look forward to collaborating with you for years to come. In addition, I want to thank Lori Solo, PT for her friendship and encouragement to enter the OTD program, which has truly inspired me to explore new areas of occupational therapy practice and occupational justice. You both hold a very special place in my heart.

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ABSTRACT

Data in the literature consistently shows most of specialty care is provided at large metropolitan, academic medical centers where there is a great enough volume of patients to support specialty providers (The Robert Wood Johnson Foundation, 2016). America occupies over 3.8 million square miles with 72% of the country classified as rural territory by the Department of Agriculture in 2017 with 20% of Americans living where healthcare provider shortages exist (Nationmaster, 2017). Poor maternal health combined with barriers in accessing quality prenatal care, place infants at greater risk for sustaining a Brachial Plexus Birth Injury (BPBI) during the delivery process. BPBI has an incidence of 1/1000 births with the potential for nerve damage to be permanent in 10-18% of cases (Chauhan, S. et al., 2014; Frade et al., 2019). Restriction on the use of telehealth results in reduced access to specialty care.

To mitigate the inequities in healthcare, this author applied key concepts found in the literature on effective educational collaborations between specialty providers and community providers to develop an online educational series (Ashburner et al., 2016; Bywood et al., 2013; Careau et al., 2008; Day et al., 2012; González-Espada et al., 2009; Mahnke et al., 2011; Shivji et al., 2011; Ray et al., 2015), for community occupational

and physical therapists in gaining important knowledge and competence for caring for children with BPBI in their own communities. This program integrates the positive benefits of building community networks for formal and informal mentoring to decrease provider isolation, to improve efficiency and effectiveness of healthcare for children with BPBIs in rural areas.

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CHAPTER ONE – Introduction

Introduction

Individuals living in rural and medically underserved areas of the United States face significant challenges in accessing specialty care for many different reasons. Access to specialty health care, including occupational therapy, can be a result of workforce shortages, barriers related to socio-economic status in addition to legislative, professional licensing and insurance barriers pending where an individual lives within the United States of America. The use of telehealth has the potential to decrease accessibility issues for the betterment of patients and families, in addition to decreasing the financial burden travel, missed time at work and other related costs for supporting other family responsibilities as found in many studies (Covert, Slevin & Hatterman, 2018; HealthyPeople.gov, 2017; Lindgren et al., 2016; Wallisch, Little, Pope, & Dunn, 2018b). These barriers play a major role in the health inequities individuals in rural and underserved areas face when in need of pediatric specialty care. A lack of specialty care providers, workforce shortages and frequent community provider isolation can make it challenging for community providers to gain the knowledge and competence in treating children with complex or rare medical conditions as a result of limited mentoring or support from interprofessional teams. (The Robert Wood Johnson Foundation in 2016) This increases the potential for children to go undiagnosed during critical periods of development, which could lead to chronic health conditions, barriers to full participation in meaningful activities and greater disability.

The aim of this inquiry was to research and better understand the barriers precluding the expansion of the use of telehealth, better understand the current health equity issues individuals in rural areas or underserved communities face to determine how to best advocate for changes to reduce these barriers for the pediatric population. This author's understanding of the real issues that pediatric patients and their families face in accessing specialty care in rural areas, comes from practicing Occupational Therapy (OT) for 25 in rural and underserved areas of New England in addition to working with marginalized populations. As a Board Certified Pediatric (BCP) OT, Certified Hand Therapist (CHT) in addition to a Sensory Integration Praxis Test therapist (SIPT), this author has served as a "specialist" consultant for many different pediatric populations and has seen first-hand how challenging it is for families to get the needed support from their local occupational therapists who may not have specialized training. Equally as important, this author understands how challenging it is for community occupational therapists in rural areas to access continuing education courses due to poor funding from employers, high costs for courses and travel demands to attend continuing education courses. Most importantly, this author believes community therapists have exceptional potential to excel when provided the appropriate mentoring and support from occupational therapists that specialize in certain areas of pediatric OT.

This author believes that with appropriate legislation to expand the use of Telehealth in the future, it could improve the efficiency and quality of health care while reducing waste, by having patients be seen in collaboration with their primary care providers and local therapists within their own community. Expanding the use of

telehealth across state lines could potentially in turn expand the medical home and medical team for individual patients, but more importantly, it would also allow specialists to better coordinate care and manage complex medical conditions (Ray, K. et al., 2015). This service delivery model would provide greater opportunities for specialty providers to educate and collaborate with community providers, which in turn improves their ability to care for other children with similar health care needs in their communities.

To move forward with this doctoral project, this author investigated the following:

- The barriers patients and families encounter with gaining access to specialty care (insurance approvals, paperwork to get insurance referrals and time/communication barriers)
- The financial burden limitations to appropriate health care creates for families and caregivers. (Greater disability requiring more support and care, chronic health conditions, hospitalizations, etc.)
- The complications that uncoordinated care causes families and children.
- The financial waste of uncoordinated care versus savings, when telehealth or eHealth (Educational or consultative collaborations between specialty providers and community providers)
- The patient/caregiver identified benefits of telehealth related to patient outcomes.

Families that this author has served have provided regular feedback over the years about barriers they have experienced in accessing pediatric occupational therapy service in rural areas. Factors include concerns about:

- Frequent loss of days worked by caregivers and school absences for patients.
- Financial burden for transportation to get to medical appointments resulting in frequent missed visits by patients with providers.
- Financial burden of needing to pay for childcare for siblings and added expenses for lodging and parking when studies or other specialty visits are not coordinated for the same day.
- Poor carry-over of recommendations by providers close to home, due to decreased knowledge or competence with treatment recommendations made by specialty providers.
- Conflicting medical recommendations (therapeutic, medication, coordination of studies) from different providers, which can result in high safety risk for patients.

- Poor access to occupational therapists or physical therapists in the community due to providers “comfort” with treating certain diagnoses without direct guidance and/or support from skilled specialists.
- Missed opportunities by therapists to assist families with gaining access to resources and alternative supports within their communities because of not having access to therapists closer to home.
- Access to recreational and alternative Instrumental Activities of Daily Living (IADLS) within the individual’s community or virtually through support groups, foundations, and blogs.

This doctoral project will present the theories and evidence gathered while studying the above barriers, though this author understands it may take several years of advocacy to change legislative and practice acts to increase access to telehealth. Therefore, the evidence prompted this author to instead, approach increasing access to OT specialty care for the pediatric population, by designing a series of online learning modules on Brachial Plexus Birth Injuries for community occupational and physical therapy providers. For clarity, it is important to note online educational platforms frequently use different terms such as “telehealth”, “telemedicine”, “e-learning” as well as “teleconferencing”. Online, interactive educational conferences researched by this author that were successful were educational collaborations where different specialty providers provided didactic activities, case reviews and case studies with community providers to improve community provider’s knowledge and self-efficacy for caring for complex or rare conditions (González-Espada, W. et al., 2009; Arora et al., 2019). The design of this doctoral project and program is based on this author’s review of the available research and evidence of successful programs that have been able to address barriers individuals in rural areas face in accessing specialty care due to provider shortages, community provider knowledge, legislative, insurance, and professional board

restrictions across state lines. It is this author's hope that this program can further expand and become a model program not only for occupational therapy, but for interprofessional pediatric care.

CHAPTER TWO – Project Theoretical and Evidence Base

Chapter 2: Theoretical and Evidence Base to Support the Proposed Project

Individuals living in rural and medically underserved areas of the United States face significant challenges in accessing specialty care for many interconnected reasons, however, telehealth has the potential to decrease accessibility issues for the betterment of patients and families. This chapter will explore the impact legislative and professional licensing barriers as well as the realities geographical and socio-economic status have on accessibility to pediatric specialty care in rural areas. The occupational therapy conceptual practice models that this author felt best supported the use of telehealth to increase access to specialty care for pediatric patients are the Model of Human Occupation (Kielhofner, 1980) and aspects of the Occupational Performance Coaching Model. These conceptual practice models will be discussed in detail followed by the evidence found in the literature regarding the effectiveness of parent education and training programs in natural environments. Finally, this author will discuss the potential benefits telehealth could have in mitigating the health care inequities individuals and families currently face.

Theoretical and evidence base to support the proposed project.

The Occupational Therapy conceptual practice models that best support the use of telehealth to increase access to specialty care for pediatric patients are the Model of Human Occupation (Kielhofner, 1980) and aspects of the Occupational Performance Coaching Model. The Model of Human Occupation (MOHO) addresses the occupational

justice and health equity concerns individuals in rural communities face compared to more urban areas, due to limited resources and insurance barriers. The MOHO is identified as an important model for supporting equal access to specialty providers via telehealth because it proposes participation in all of life's occupations and is individual specific. MOHA also believes occupations are dependent on the interconnection between the individual's volition, values, and their habituation within their personal and environmental contexts. When children are born with complex or rare medical conditions and reside in communities or environments where there is little access to specialty care, timely identification and diagnosis of these conditions is imperative for potential, positive functional outcomes. (Chowdhury et al., 2007; Snow, 2005). It is well understood that personal characteristics and environmental factors are interconnected, particularly for those that live in rural, or resource poor areas of our country and the world. Environmental effects on personal characteristics cannot be denied, especially when considering how the impact of political and economic factors influence an individual's self-perception and understanding of one's right to advocate for their child's equitable access to available resources. The MOHO takes into consideration the influence of cultural contexts and individual's understanding and acceptance of injury, illness, and disability. This notion further supports the use of telehealth to access specialists while collaborating with community providers so that proper patient and family centered care can occur efficiently and effectively (Kielhofner, 1980).

In addition to the personal and contextual factors, the MOHO can address patient challenges or barriers related to "Body Structure and Function", "Activities" and

“Participation”. By using this model, an individual’s physical needs can be addressed to enable full participation in occupations. There are similarities with some aspects of the Biomechanical model, however, the MOHO considers these aspects in context of the individual’s occupational wellness. The Biomechanical Model, which was most highlighted during the mechanistic period with several different modifications by different professionals in different areas of practice, is primarily concerned with musculoskeletal issues with the focus being on prevention and/or restoration of a person’s capacity for participation in everyday functional mobility. This biomechanical model is often used when individuals are rehabilitating from an injury or surgery, and often requires patients and providers to follow protocols specific to conditions, however, specialists following the MOHO are not precluded from incorporating these types of protocols into their care of individuals (Dutton, 1998). Allowing children and families to have access to specialists in the patient’s local communities, better permits specialists to work with families and community providers to deliver the needed support and education to the community provider. This can improve the quality of care for individuals in their own community with musculoskeletal conditions. This supports the philosophy discussed in the telehealth literature of “upskilling” rural providers competence with caring for a wider range of patients with complex or rare medical diagnoses (Arora et al, 2011; Callas, 2000; Jackson et al., 2008; McConnochie et al.,2010).

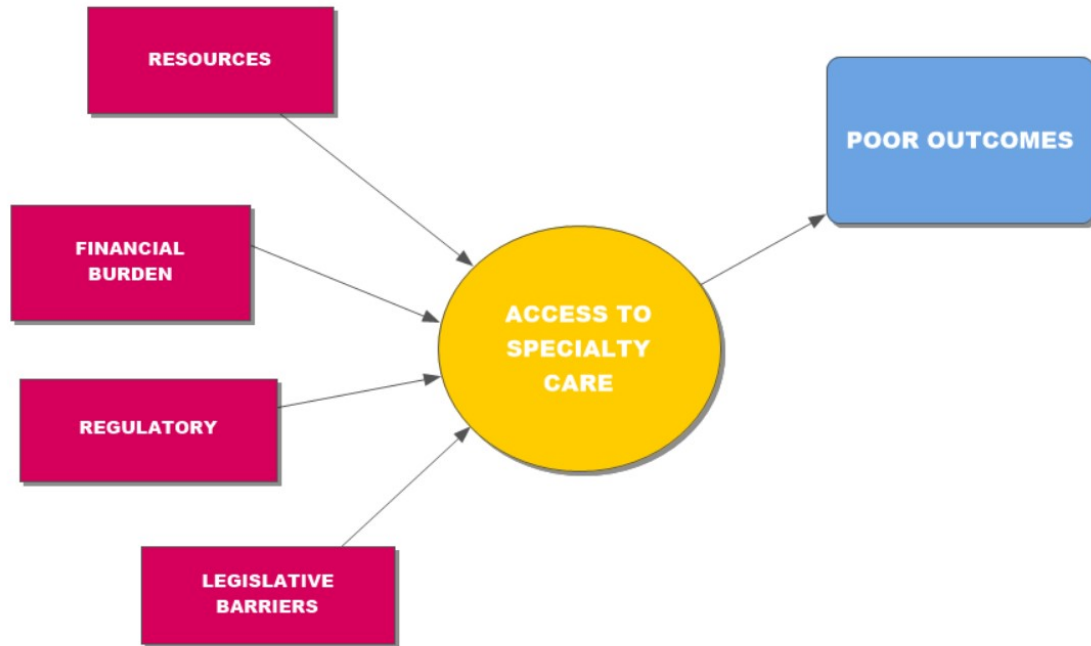
In reviewing the MOHO, therapeutic strategies that are felt to be important aspects for clinicians to integrate into practice include, validating patient’s concerns, helping individuals identify their own goals, providing feedback and advising without

directing the patients/individuals. This lends itself to the development of a trusting relationship between the individual and the specialist who then can act as a “coach” to encourage problem solving to increase self-efficacy in the individual, family, and community provider. These concepts overlap with the Occupational Performance Coaching Model (OPC) (Graham, Rodger & Ziviani, 2009), which is a collaborative approach between trained providers and parents, stemming from enablement-oriented theories (Townsend & Polatajko, 2007). Graham et al. (2009) created the Occupational Performance Coaching Model based on a few assumptions that had been tested within the fields of occupational therapy, behavioral sciences, and adult learning. The OPC endorses the notion that individuals show greater interest in taking part in programming or interventions, when they feel they are in control of setting their own goals. This assumption is not only well founded in our occupational therapy framework because the nature of this process is parent-child centered (Hanna, K. & Rodger, S. 2002), but it is also well recognized as a key component in adult learning theories and behavioral science (Knowles, 1970). This assumes individuals need to feel as though they are in control of their own experience, consistent with Andragogy, an adult learning theory developed by Malcolm Knowles in the 1970s. Individualized, facilitated parent reflection increases the individual’s ability to learn new information and/or skills, identify and adapt to situations within their environment, which ultimately leads to greater competence with carryover of new skills within personal and family routines (Graham, 2009). The second assumption takes the perspective that when individuals feel they are in a trusting relationship with their coach or trained provider, it allows for better collaboration and connectedness,

which leads to more open communication. This assumption takes the perspective that parents are then more open to feedback on their personal performance with implementing newly learned skills (Graham, 2009). This assumption has proven to be true in many different types of coaching programs, across many different industries such as mental health, business, social sciences as well as in education and medicine (Ammentorp et al., 2013; Elliott, 2011; Grant, 2003; Klippel, 2006; Olsen & Nesbitt, 2010).

When OPC is used, the key change in the parent comes when the parent employs strategies that will enable lasting occupational change for themselves and their child. (Townsend & Polatajko, 2007). It is through the collaborative process of facilitating a parent's understanding of how to analyze and reflect on tasks, themselves, their environment as well as their child's motivations, that the parent then gains the skills needed to be more flexible with adapting and modifying themselves, and the environment, for their child's optimal participation, satisfaction, and success.

In conclusion, the Model of Human Occupational serves as a fitting model to address the resource barriers outlined in Figure 2.1 that limit children and family's access to specialty care, including financial, insurance and reimbursement restrictions and state legislative barriers related to provider licensure all while keeping patients and families personal and environmental contexts at the forefront.

Figure 2.1 Barriers to access

Though this author had anecdotally developed hypotheses in the past about the most common barriers that children and families with BPBIs face when trying to access specialty care (Figure 2.1), this author developed 3 guiding questions to fully explore the literature to better understand how to approach program development to decrease these barriers. These questions included:

- Is there evidence that access to specialty care through telehealth is limited by state legislation and licensing boards?
- Is there evidence that decreased access to pediatric specialty care leads to poor outcomes?
- Do social and economic resource barriers limit access to pediatric specialty care in rural communities or areas of high childhood poverty

Legislative and professional licensing barriers

Access to specialty care using telehealth has increased since the implementation of the Affordable Care Act in 2010, as well as through standards set by the Centers for Medicare and Medicaid Services (CMS) and the Joint Commission, which encouraged the use of telehealth at the federal level. Unfortunately, though telehealth is approved for use, there are well documented barriers to implementation in the literature. Medicaid programs are managed at the state level, therefore laws related to the scope of practice and types of specialty care providers that are permitted to use telehealth (Fathi, J., Modin, H. & Scott, J. 2017; Olson, C. & Thomas, J. 2017; Robert Wood Johnson Foundation, 2016). States also vary in the types of health insurances offered and variations in covered medical services. Individual states also vary regarding provider licensure, approved provider and client/patient locations during the telehealth visit and the type of telehealth being used i.e., synchronous, asynchronous, mobile health and eHealth and remote monitoring telehealth (Fathi et al, 2017; Duan, C., Kane, J. & Watney, C., 2018). There are also variations from state to state in what is considered an approved patient “originating” location and if providers are allowed to conduct initial evaluations via telehealth versus in person (Fathi et al, 2017; Olson, et al., 2017; Robert Wood Johnson Foundation, 2016).

The Health Policy Brief published by The Robert Wood Johnson Foundation in 2016 reported 20% of Americans live in areas where there are significant shortages of physician and health care specialist, noting only 9% of physicians practice in rural areas, therefore, access to specialists may be limited not only across state lines, but within large

rural states where families have limited means for transportation to travel large distances. In addition to the varying state requirements listed above, specialty providers providing the telehealth must have the same hospital or outpatient clinic credentialing and privileges where the patient is located, and in some instances, CMS requires the patient to be physically located at an approved CMS site. (Adler-Milstein et al., 2017; American Academy of Pediatrics, 2015; Duan et al., 2018; McSwain, S. & Marcin, J. 2014; Olson et al., 2017; Hansen et al., 2015). Additionally, providers also need to take into consideration malpractice insurance coverage for their telehealth services (American Academy of Pediatrics, 2015; Olson et al., 2017).

In 2016, The National Conference of State Legislatures made the decision that individual states could establish their own requirements for reimbursement for telehealth services (Adler-Milstein, J., Kvedar, J. & Bates, D., 2017). Adler-Milstein et al. (2017) investigated how hospitals across the country adopted the use of telehealth and found there was large variability in the adoption of telehealth noting states that developed policies that required private payer reimbursement for telehealth services and parity payment requirements (equal reimbursement for telehealth visit as in person visit) were the most likely to adopt telehealth technologies. The American Medical Association in 2017 noted that although the Interstate Medical Licensure Compact formed in 2013 was intended to decrease the barrier that physicians needed to be licensed state to state by creating licensure compacts, only 22 states had joined the Interstate Medical Licensure compact by 2017, due to licensure barriers at the state level (American Medical Association, 2017). In *Perspectives of the ASHA Special Interest Groups*, Grillo (2019)

outlined physicians have the ability to practice in 20 states with compacts with pending legislation in 5 states, while nurses have compact licensure in 20 states, and 5 states for Physical Therapists. AOTA and ASHA are currently attempting to develop interstate licensure compacts, demonstrating there is a large gap for telehealth use in the allied health professions.

Unfortunately, the literature consistently shows the majority of subspecialty care is provided at large metropolitan academic medical centers where there is a great enough volume of patients to support specialty providers. The shortage of subspecialty care in rural areas was highlighted in The Health Policy Brief published by The Robert Wood Johnson Foundation in 2016, where they noted 20% of Americans live in areas where there are significant shortages of physicians and health care specialists, with only 9% of physicians practice in rural areas. As a result, there is clear evidence that individuals living in rural states or remote areas of certain states, are at the highest risk for limited access to specialists through telehealth, particularly across state lines due to the barriers outlined above, perpetuating health disparities for children living in more rural areas of the country.

Socio-economic status and impact on access to pediatric specialty care in rural America.

Socio-economic status plays a significant role in an individual's ability to access medical care, supportive community services and insurance for a whole host of reasons. This ultimately creates significant barriers for quality of life and overall mortality.

As stated above, the literature consistently shows most of subspecialty care is provided at large metropolitan academic medical centers where there is a great enough volume of patients to support specialty providers (Gans et. al, 2013; Marmot, & Wilkinson, 2006; Robert Wood Johnson Foundation; 2016) as was highlighted in The Health Policy Brief published by The Robert Wood Johnson Foundation in 2016, where they noted 20% of Americans live in areas where there are significant shortages of physicians and health care specialists, with only 9% of physicians practice in rural areas. The shortage of healthcare professionals in rural areas, particularly primary care physicians, adds another layer of difficulty with accessing subspecialty care as many insurances require referrals from the PCP to approve visits with specialty providers. Heisler (2013) referenced Health Professional Shortage Areas as problematic not only for patients, but for rural providers as well, due to the isolation and shortage of supporting staff to better coordinate care. To further give perspective of the challenge that geography plays in accessing specialty care, Nationmaster (2017) outlined America occupies over 3.8 million square miles with 72% categorized as rural territory by the Department of Agriculture (2017), which represents approximately 42 million people in rural areas. There are many studies that consistently show individuals in rural areas have higher rates of obesity, diabetes, poverty, and unemployment with 25% of families with children in rural areas falling into the category of deep poverty. Some common social and health determinants for individuals in rural areas include low levels of education, low socioeconomic status, higher levels of unemployment and often reduced means of transportation, placing them at greater risk of poor health outcomes (HealthyPeople.gov,

2017).

Hirko et al., (2020) point out that it has also been noted that 33% of Americans do not have access to high-speed broadband internet with downloadable speeds of at least 25 megabits per second, which the Federal Communications Commission defined as the needed speed for proper telehealth use. Unfortunately, rural schools, libraries and community health clinics often have decreased access to high-speed broadband internet so despite efforts to gradually increase the number of “potential originating sites” where children can be located to access specialty care through telehealth, access is not always possible due to limitations in broadband internet access at the community level. Therefore, there is clear evidence that children and individuals living in rural states, or remote areas of certain states, are at the highest risk for limited access to specialists through telehealth, due to differences between states Medicaid coverages, limited PCPs, limited broadband access in addition to the mentioned barriers legislative, insurance coverage, professional licensure and state practice act barriers outlined, which only perpetuates health disparities and health injustices.

Effectiveness of parent education and training in natural environments

To further study the literature around the effectiveness of direct parent education in a natural environment, research articles were reviewed regarding parent training versus parent coaching. It is interesting to note there is more literature emerging around the difference between the effectiveness of parent training versus coaching strategies. The literature this author reviewed shows parent training is typically conducted by a provider

with the goal of increasing the family's ability to replicate or reproduce a predetermined intervention or protocol. In comparison, parent coaching stems from family centered care in that it is a collaborative process where the parent and provider are equally collaborative in the process (Ziegler, Dirks, & Hadders-Algra, 2019; Zielger & Hadders-Algra, 2020).

Family centered care, particularly in the natural environments using coaching, is an intervention approach intended to build on family strengths and resources while increasing a family's ability to identify their own needs and goals. The role of the coach is to support the parent's ability to identify their needs, facilitate reflection and problem solving to increase the parent's capacity to independently develop solutions to meet their child and family's needs. In the process, the coach remains nondirective, however, takes part regularly in guided reflection with the parent. In addition to allowing the parent time to practice and problem solve about barriers that appear to be limiting their ability to meet their goals, several studies have shown that coaching allows parents to develop greater understanding of possible solutions and building competence to solve problems on their own (Dunn et al., 2017; Little, Pope, Wallisch & Dunn, 2018a; Rush & Sheldon, 2011). There is strong evidence that shows parents better understand their children and their diagnoses when participating in coaching models and feel they are more a part of the team because they have a significant role in the intervention and decision-making process as opposed to when their child is receiving therapy in a school or clinic situations (Rush & Sheldon, 2011; Foster et al., 2013; Law et al., 2003). In Ashburner et al.'s research study (2016), the authors' intention was to investigate parent and service

provider's perception of technology to provide "remote" versus "face-to-face" early intervention service programming for children with autism spectrum disorders (ASD) in remote areas of Australia. Similar to studies conducted by Graham et al. (2009; 2014) in Australia, which utilized telehealth or remote technology and the Occupational Performance Coaching Model, Ashburner et al. (2016) found one of the most consistent themes identified by parents, local service providers and the ASD specialists was the value of being coached. Parents, local and remote service providers all identified that there was more time to collaborate to develop family specific resources, problem solve barriers, develop strategies, and practice strategies in a supported situation with parents in their homes, compared to typical clinical settings. Local service providers and parents also recognize that remote coaching allowed for "upskilling" of the local providers in that they were able to work with ASD specialists with more experience allowing for greater access to training, knowledge and ASD specific resources. As a result, this increased both parent and provider self-efficacy and competence (Ashburner et al., 2016; Graham et al. 2009; Graham et al. 2014).

In studies that included telehealth delivery interventions using coaching models where parents and children were in their homes, parents report they felt better able to apply techniques and interventions into their daily routines while in the natural setting compared to when learning in clinic settings (Ashburner et al, 2016; Wallisch, Little, Pope, & Dunn, 2019). Parents and providers also reported the delivery of the intervention model through telehealth, was highly compatible with family life as it allowed for more flexibility than in-person therapy sessions, resulting in decreased stress

and family life disruption. Delivery of interventions through telehealth has also been shown to decrease financial burden on families and service providers caring for children in remote or rural areas, decreased missed therapy sessions and improved continuity of care (Wallisch et al., 2019 p. 19) (Covert, Slevin & Hatterman, 2018; Lindgren et al., 2016; Wallisch, Little, Pope, & Dunn, 2018b).

In reviewing the literature, several different types of coaching models and types of parent education programs in the natural setting were identified as effective for many different reasons, though Zeigler et al. (2020) point out in their review paper there are inconsistencies in the definition of coaching and terminology used in the intervention process, in addition to inconsistencies with the relationship between providers and parents/families, which make it difficult to successfully implement and measure outcomes using coaching models. As a result, though the literature is showing increased parent self-efficacy, competence and reported quality of life from coaching models within natural environments compared to clinic-based services for children with complex medical needs, the key ingredient for success using coaching models is proper provider training, to ensure providers are knowledgeable and competent with the provision of family-centered practice.

Based on the literature reviewed as outlined above, and the continued challenges providers face regarding implementation of telehealth, this author has chosen to explore alternative ways to decrease inequities as they relate to accessing occupational therapy specialty pediatric care with a specific focus on Brachial Plexus Birth Injuries (BPBI). As an occupational therapist (OT) who is Board Certified in Pediatrics and a Certified

Hand Therapist who works on an interdisciplinary team in the Brachial Plexus Program at Boston Children's Hospital, this author regularly sees how challenging it is for families in rural and underserved areas to access occupational and physical therapy care when their child has sustained a BPBI. Some rural and underserved areas have occupational therapists (OT) and physical therapists (PT), however, those therapists do not feel they have the knowledge or comfort level for treating children with BPIs, therefore, the focus of my doctoral project was to study the evidence to support the utility of telehealth or tele-education for development of an online community provider education series, specifically for the BPBI population as a means to decrease the barriers these children and families face in accessing specialty care.

To better understand community provider's needs, this author completed a social assessment via a google docs survey as a means of engaging the community in the development of the online educational modules. In the next chapter, this author will guide the reader through the reviewed, existing literature beyond the scope of the occupational therapy profession and discuss the types of community collaborations that exist between specialty providers and community providers, which support ongoing learning/educational programming to increase community provider's competency with taking care of more complex pediatric cases. In addition, this author will discuss how the identified key ingredients identified in the different studies by community providers in building knowledge and competency were then carefully considered and applied to the development of the Brachial Plexus Birth Injuries: Community provider learning modules by this author.

CHAPTER THREE – Overview of Current Approaches and Methods

Access to occupational therapy services in rural and underserved areas of our country is a big obstacle that many children and families face. Access to pediatric specialty care for cardiac, oncology, neonatal, neurological, and mental health conditions is also well documented in the literature. This author reviewed literature across these specialties to determine which approaches have been used by the different professions to address barriers to health equity.

Guiding questions this author used included:

1. Is there evidence that telehealth and eHealth (specialty provider to local provider education and collaborative working relationships) can increase local provider's knowledge and competence with managing care for children with complex or rare medical conditions?
2. What strategies have been shown to increase parent competence and self-efficacy with carryover of home program recommendations?
3. Is there evidence that access to telehealth for the provision of care for children and families living in rural areas increases family's active participation in health care and shows cost savings and patient satisfaction?

Keywords and terms this author used in the literature search included: Pediatric Specialty Care, Telehealth, Health inequities, parent training, eHealth, ECHO health program, telemedicine reimbursement and state policies, and telehealth and patient satisfaction. The literature was also searched for studies and articles in the *American Journal of Occupational therapy* for the last 10 years, to see if programs to address workforce shortages and/or programs to increase community provider competency existed, however, results were very limited. To extend beyond the profession of OT, this author completed similar searches in the following journals: *American Medical*

Association Journals, Journal of Telemedicine and Telecare, Journal of Pediatrics, Pediatrics, and a variety of journals related to public health.

Telehealth, eHealth, and impact on increasing community provider's capacity.

There is growing evidence to show both the need for, and benefits of, developing telehealth collaborations between specialty providers and rural community providers. The collaborations can improve access to specialty care, decrease delays in patient medical diagnosis and proper treatment, and decrease the financial and travel burden on families and children (Bywood et al., 2013; Careau et al., 2008; Day et al., 2012; Gonzalez et al., 2009; Hall et al., 2009; LaBarbera et al., 2013). Most importantly, development of such collaborations better support the community provider's acquisition of knowledge and competence to care for complex pediatric patients in their own communities. There is evidence that initiatives and collaborations between academic or larger medical institutions and community hospitals, healthcare centers, pediatricians and allied health providers have been effective in increasing provider knowledge and competence, while increasing patient's access to quality healthcare (Hall et al., 2009; LaBarbera et al., 2013). In a prospective study, Arora et al. (2011) were able to show the effective use of the Extension of Community Healthcare Outcomes (ECHO) model, a program intended to increase the care for underserved populations with complex health problems through training of primary care providers via videoconferencing. Arora et al. (2001) noted adult patients with Hepatitis C virus (HCV) infection were as effectively treated and managed by their community providers as those patients treated by specialists at the University of New Mexico.

Barriers to accessing pediatric subspecialty care are widely reported to be an issue in rural communities in the United States, Canada, Australia and many remote, rural and poor areas of the world. Several studies that this author reviewed, focused on the use of telehealth, eHealth and remote educational offerings between larger pediatric medical institutions and community providers (pediatricians, neonatologists, nurse practitioners, allied health professions and physicians working at small community hospitals) to improve access and quality of care within patients' local communities (Ashburner et al., 2016; Bywood et al., 2013; Careau et al., 2008; Day et al., 2012;). There is much literature to show that when telehealth or teleconsultations with pediatric subspecialists are available, there is a considerable decreased need to transfer children from community hospital emergency rooms to larger medical institutions, far from the family's home (Hall et al., 2009; LaBarbera et al., 2013). The development of such collaborations, or agreements, between larger medical institutions and community hospitals, allows greater opportunity for specialists to regularly educate community providers and support them in clinical decision making, best practice, and new research findings, leading to stronger professional relationships (Bywood et al., 2013; Careau et al., 2008; Day et al., 2012; Gonzalez et al., 2009; Hall et al., 2009).

One collaborative program that has been shown to be effective in trying to decrease rural provider isolation through online educational opportunities is the Pediatric Physician Learning and Collaborative Education, (Peds PLACE) (Gonzalez-Espada et al., 2009). This program was "established in 2007 with 5 main goals: (1) to support practitioners in rural areas of Arkansas; (2) to build relationships between rural

practitioners and tertiary care pediatric specialists; (3) to learn the experience of rural practitioners; (4) to translate current research findings into useful advice and community health improvement; and (5) to improve the health care of medically underserved children in Arkansas” (e476-e475). Peds PLACE programming is offered through the telemedicine network operated by the Center for Distance Health at the University of Arkansas for Medical Sciences (UAMS). Program offerings can be accessed on 150 units, which are linked to the Arkansas Department of Health Bioterrorism Network, in all 87 hospitals and 43 county health units in Arkansas. Faculty physicians from Arkansas Children’s Hospital (ACH) and UAMS present on a wide variety of common pediatric problems through interactive presentations, discussions, and visual presentations (Gonzalez et al., 2009 e477). Results from their program evaluations showed good participation and satisfaction with the platform by community providers. Community providers who participated in the Peds PLACE online educational sessions provided critical feedback that they found educational sessions that included dynamic discussions and case presentations in conjunction with content the most appreciated and useful for direct application to practice. The benefits of dynamic educational sessions and discussions were also found to be the most helpful by rural pediatricians in separate studies, which this author will further discuss later in this paper (Bywood et al. 2013; Ray et al., 2015).

Telehealth and tele-education conferences have also been shown to be very effective for supporting neonatologist, pediatricians, lactation consultants, community occupational and speech and language pathologist and family practitioners caring for

newborn babies (Ashburner et al., 2016; Bywood et al., 2013; Careau et al., 2008; Day et al., 2012). One successful program that was developed by the University of Arkansas for Medical Sciences (UAMS) is a tele-nursery program, initially started through a monthly tele-education conference to support community provider's ability to care for newborn babies. Eventually, the success of the tele-nursery program prompted the larger nurseries in Arkansas to collaboratively develop "tele-nursery rounds" to assess and triage infants across the state of Arkansas. The goal of the program is to allow for better collaboration and coordination between nurseries in Alabama to ensure infants can efficiently be moved to higher or lower acuity NICU care (Level 1- Level 3). The "tele-nursery rounds" better allows for children to be serviced as close to home as possible, with the appropriate level of medical support. The program was able to expand the community network using telehealth and tele-education, and with increased professional knowledge through community provider support, Arkansas has been able to regionalize neonatal care, which achieves the goal of increasing access to care and decreasing family burden, which is a strong interest of this author (Hall-Barrow, et al., 2009).

There is strong evidence that rural pediatricians, working with children and families, also feel there would be great benefit to increasing collaboration with specialty providers through telehealth consultation, education, and collaboration (Bywood et al. 2013). In Ray et al.'s (2015) qualitative study, the researchers sought to better understand what recommendations rural pediatricians had regarding collaboration with subspecialists to optimize care. Key themes that emerged were pediatricians felt utilization of telehealth for subspecialty care would be very helpful for "patient-

subspecialist encounters and generalist-subspecialist communication” through modalities such as “live video telemedicine, telehealth triage systems, physician access hotlines, remote EMR access and electronic messaging systems” (Ray et al., 2015, p. 627).

Consistent with feedback gathered from community providers attending the PedsPLACE educational presentations, rural providers report greater benefit from direct case discussions with specialty providers, with rural pediatricians reporting 70% of the referrals they make to pediatric subspecialists are intended primarily for “advice”.

Opportunities such as these are consistent with the positive benefit rural pediatricians and neonatologists at community hospitals reported with live participation in telehealth and tele-rounds, inclusive of discussions and case presentation with subspecialists because it better allows for advancement of community provider’s knowledge and competence with applying education directly to patient care (González-Espada et al., 2009; Shivji et al., 2011; Ray et al., 2015).

Pediatricians and primary care providers in many studies reported telehealth consultations about their patients, and participation in specialty telehealth visits with their patients, would greatly improve their ability to manage and coordinate children’s care within their own practice or community (Bywood et al., 2013; Careau et al., 2008; Day, K., & Kerr, P.2012). Pediatricians in these studies identify the potential for substantial cost savings telehealth could have on decreasing unnecessary referrals to the specialty providers. Improving timeliness of referrals may ensure a patient’s care is efficient and effective while decreasing the potential financial burden on families (Mahnke et al., 2011; Ray et al., 2015; Smith et al., 2007; Shivji et al., 2011).

Though a few of these studies were conducted over 5 years ago, telemedicine and teleconsultation programs have been shown to decrease the need for costly transferring of children to larger tertiary hospitals long distances from their home (LaBarbera et al., 2013; Mahnke et al., 2011). In the study conducted by Mahnke et al. (2011), results showed substantial cost savings with the use of asynchronous teleconsultation with 43% of teleconsultations between pediatric physicians and subspecialties preventing the need for face-to-face subspecialty evaluations. In Mahnke et al.'s study (2011), teleconsultation prevented the need to transport children and families between Pacific Islands for subspecialty care, which is typically very expensive. This study was sponsored by the Department of Defense between 2006-2009 with the goal of increasing access to care, quality of care, and cost savings. Key findings by Mahnke et al. (2011) illustrated the positive benefits telehealth had on increasing community provider's knowledge, for example, 60% of teleconsultations answered referring physician's questions with 65%- 84% of teleconsultation resulting in proper diagnosis and/or treatment modifications (p. 4).

In a study by LaBarbera et al. (2013), the researchers found telehealth consultation between a non-pediatric community hospital and a tertiary pediatric intensive care unit (PICU) not only decreased the need for transferring of patients to tertiary hospitals long distances, but found telemedicine aided in proper diagnosing and identification of the severity of the illness, which led to fewer pediatric patient transfers to higher acuity units (PICU). Over time, they were able to show overall decreased transfer rates, which in part they felt could be related to increased community provider

knowledge and ability to care for more complex pediatric cases within their own community.

Studies have shown pediatricians and community providers, similar to adult primary care providers, report it is much harder to streamline effective communication between generalist-providers and subspecialty providers when telehealth is not present, which increases the potential for uncoordinated care and poor timing and quality of care (Bywood et al., 2013; Careau et al., 2008; Day et al., 2012; Moffatt et al., 2010; Smith et al. 2009). Shivji et al.'s (2011) pediatric surgical telehealth pilot study was conducted in Canada where the government supports their citizen's healthcare, unlike the United States, where individual state legislation, professional licensure and insurance barriers make telehealth challenging. The focus of Shivji et al.'s (2011) pilot study was to assess patient and provider satisfaction with the use of telehealth for pre- and post-surgical evaluation and care, with the primary healthcare providers and patients at one location and the pediatric surgeons at The Stollery Children's Hospital in Edmonton, Alberta. The goal of the program was to increase access to specialty care, reduce travel costs and time burdens for children and families, but also to provide opportunities to build healthcare provider's capacity in remote and rural areas. This was in response to the recognized challenge many children and families face in accessing specialty care in many Canadian provinces, due to the long distances between patient's homes and children's hospitals in the central and northern regions of Alberta and other provinces. Canada promotes the use of telehealth to reduce costs for travel and improve efficiency of care for children and families. In Shivji et al.'s (2011) study, 94% of patient respondents

reported telehealth increased their access to healthcare because 97% lived more than 200 km from the city with 77% living more than 400 km away. Ninety nine percent of respondents reported the telehealth option saved them money with 51% reporting a savings of \$101-\$500 dollars for travel alone, not considering lost wages, cost for accommodations, and food. Eighty Nine percent of respondents who participated in the study indicated the use of telehealth allowed them to obtain access to pediatric surgery services much sooner than if they had to travel to the city for the same consultation. The authors also found rural health providers (100%) were also satisfied with telehealth visits to increase timely access to specialty care as well as the cost savings it provides families all while increasing collaboration and communication with the specialty provider for ongoing care of patients.

Key ingredients to increase parent participation, competency, and self-efficacy for greater carry over of recommendations.

Research is showing family-centered care, which is inclusive of information sharing, collaborative goal setting, problem solving processing and guided reflection for application of newly learned skills, is one of the most effective ways to increase parent engagement or “buy-in”. It has also shown to be effective in building parent competence and self-efficacy for many different reasons. Considering the importance of the “family” being the center of any intervention, many different coaching models have been developed and studied over the years to determine effectiveness in changing parent’s competence and self-efficacy. Given this author’s doctoral project focuses on improving access to specialty care, special consideration was given to interventions that have been

shown to be effective in building parent confidence and competence, particularly for parents living in rural and underserved areas with limited access to specialty care. For this reason, this author has focused on interventions that bridge this gap in access, by studying the effectiveness of providing parent education and training using telehealth.

Several studies have been conducted on parent training or coaching interventions, by a wide variety of health professionals over the years. Some studies focused on the use of coaching through telehealth to support families with children with autism spectrum disorder, others focused on supporting mothers with fragile infants in need of lactation and specialized feeding support following discharge from the NICU, while others focused on coaching of parents with children with complex medical conditions (Garne, K. et al, 2016; Graham et al.,2009; Graham et al.,2013; Uscher-Pines, L., 2017; Vismara et al., 2013). Interventions in these studies were delivered either intermittently through face-to-face coaching or through remote “parent training or coaching” employed coaching models.

Coaching models, which are family-centered and strength-based, are intended to address occupational performance deficits that a parent, child or family unit may be experiencing, and are consistent with family-centered care. This is a collaborative process between a therapist and parent-child (Graham et al., 2009; Graham et al., 2013; Little et al., 2018; Vismara et al., 2013; Wallisch et al., 2019). As previously discussed in this doctoral project, one coaching model this author explored is the Occupational Performance Coaching approach developed by Graham et al. (2009). OPC stems from the Enablement-Oriented theories (Townsend et al., 2007), in addition to the “International

Classification of Functioning, Disability and Health Model (World Health Organization, 2001) and occupational therapy's Person-Environment and Occupation (PEO) models (Law et al., 1996) (Graham et al., 2010; Graham et al., 2017; Graham et al., 2009; Graham et al., 2013). In addition, the OPC model is appealing because it has been recognized that the model also has components consistent with the Self-Determination Theory (SDT) (Ryan et al., 2000), which is also consistent with family-centered care. The combination of these theories and models are particularly important considering an individual's motivation can significantly impact change (Graham et al., 2015).

Therapists utilizing the OPC follow a structured protocol that is inclusive of three domains including emotional support, information exchange and a structural process with the purpose of increasing the parent's capacity and competence with identifying goals that are pertinent to themselves, or their child, within their personal and environmental contexts.

Graham et al. (2009; 2013) and Vismara et al., (2013) separately studied the effectiveness of parent training through telehealth with programming that included concepts from family-centered care. Graham et al. (2009; 2013) developed and studied effectiveness of Occupational Performance Coaching on parent competence and self-efficacy while Vismara et al. (2013) drew from coaching interventions utilized in several previous studies. In addition to studying the effectiveness of coaching, Vismara et al. (2013) also analyzed instructional design of adapting long-distance learning on the computer, literacy demands and the importance of "chunking" information into fewer clicks when navigating online educational modules, to avoid causing participants to be

cognitively overwhelmed (Feil et al. 2008; Kameenui & Carnine, 2001). Both Graham et al. (2009; 2013) and Vismara et al. (2013) examined how the coaching approach with parents would influence their acquisition of knowledge and competence with implementation of interventions within their natural environments, based on previous studies (Feil et al., 2008; Fixsen et al., 2009; Schoenwald et al. 2004; Thomas et al. 2009; Wood et al. 2007).

Key ingredients that Graham et al. (2009; 2013) and Vismara et al. (2013) identified as beneficial from parent feedback regarding the use of “coaching” during intervention sessions was the positive benefits of facilitated parent reflection on information learned through online learning modules as well as guided reflection and coaching throughout the parent’s experience with implementing skills learned the previous coaching session. In both studies, this time for open discussion was found to increase open communication and collaboration between the therapist and the parent, on parent-child specific needs. In both studies, facilitated parent-reflection allowed parents to learn how to process their own experience, which will ultimately lead to more efficient identification of barriers and development of strategies for successful implementation of intervention in their own home setting. Consistent with other research findings (Little et al., 2018; Mahoney et al., 2004; Siller & Sigman, 2002; Wallisch et al., 2019), Vismara et al. (2013) point out in their discussion that through this training, parents felt they gained greater awareness and sensitivity to reading their child’s cues and were more responsive to positive learning moments within their daily routines and across settings.

Graham et al. (2009; 2013) and Vismara et al., (2013) both found in their studies

that parent coaching that took place during “live” implementation of *previously learned* interventions with their child, reinforced learned skills through repeat practice, which in turn increased parent acquisition of correct techniques, ultimately increasing parent confidence and competence. Similarly, live coaching of parents while implementing *newly learned* topics, was helpful in enhancing parent’s understanding of new techniques. Parents reported this led to an increased likelihood of correct implementation of interventions in their daily life the following week. Vismara et al. (2013) point out that previous studies demonstrated it was important to have ongoing training to sustain new skills (Fixsen et al., 2009; Schoenwald et al. 2004), therefore, Vismara et al. (2013) also felt it was important to include follow up sessions, to reinforce previously learned skills.

Unfortunately, instances when coaching is not properly implemented using the key components outlined above, there likely will be poor implementation of parent coaching, dissatisfaction and poor carry over as was found by Ziegler et al. (2020). Coaching requires adequate training and maintenance of skills (or fidelity), across providers to ensure there is consistency with this approach. Unfortunately, barriers to ongoing training can be problematic for providers and agencies if this type of training is not considered an essential part of the job.

Conclusion

As has been discussed throughout, there is significant evidence that increasing access to telehealth has been shown to increase community provider competence with caring for children through tele-educational and teleconsultation with specialty providers resulting in a significant cost savings for families for many reasons. Parents living in

rural or underserved communities consistently report greater satisfaction with the use of telehealth when they do not have to miss days from work as well as when they do not have to cancel appointments when other children in the family were sick or when other competing family responsibilities came up unexpectedly (Ashburner et al., 2016; Baharav et al., 2010; Covert et al., 2018). Families also reported better ability to carry over interventions recommended by therapists because activities that are completed over telehealth are family and child specific and are relevant to parent goals (Ashburner et al., 2016; Baharav et al., 2010), which is consistent with family centered care and adult learning theories. Parents in many studies (Ashburner et al., 2016; Graham et al., 2009; Graham et al., 2013; Little et al., 2018; Vismara et al., 2013; Wallisch et al., 2019) reported it was particularly helpful to have guidance with proper implementation of interventions when direct guidance was provided in real time, even if the specialty provider was remotely located. In addition, there have been some reports from families that they often had difficulty carrying over recommendations made by therapists in clinic settings because they were either not part of the session with their child or because they would not be able to replicate activities in the home or community environment.

Based on the literature reviewed to answer these questions, this author began a social assessment with community provider engagement to determine the educational needs of community occupational and physical therapists who currently work with, and/or anticipate working with children who have sustained a Brachial Plexus Birth Injury. The next chapter will guide the reader through this author's proposed program taking into consideration feedback from the Community Provider's Feedback Survey

regarding Brachial Plexus Birth Injuries, specific learning modules, learning activities, and outcome goals in addition to important theories to engage the adult learner.

CHAPTER FOUR – Description of the Proposed Program

Basis of the proposed program

Brachial Plexus Birth Injuries (BPBI) occur in approximately 1/1000 births (Frade et al., 2019) with the likelihood of BPBI being permanent in 10-18% of cases (Chauhan, et al., 2014). Obesity rates are high in young women in poverty and marginalized populations and as a result these women in poverty are at higher risk for developing diabetes in pregnancy, which can lead to macrosomia (high birth weight) which can lead to greater possibility for shoulder dystocia (Frade et al., 2019), though this is not the only cause of shoulder dystocia. It is not uncommon for children born with a BPBI in rural areas to have poor access to specialty care providers. It is also very common for this to be a rare diagnosis for OT and PT community providers. As a result, the child's care may be delayed in relation to proper identification and timely referrals for surgical and non-surgical treatments.

Given all the social economic and health disparities children and families in rural areas face, this author has developed and is proposing a series of online educational modules on BPBI for community providers. As was previously discussed, there have been strong, positive outcomes reported in the literature about telehealth, tele-educational and teleconsultations between subspecialists and community providers to increase knowledge and competence with caring for children with complex medical conditions within their community. This program was designed and developed for community occupational therapy and physical therapy providers with the end goal to support families with a child who has sustained a BPBI. The health objectives at the heart of this program

are to: 1. Decrease the risk of soft tissue and bony deformities, 2. Reduce the risk of limited participation and socialization, 3. Decrease the risk of depression and obesity and 4. Decrease the risk for barriers in vocational opportunities for children with a BPBI. The main goal of this educational program is to help with increasing community providers' (priority population) understanding and knowledge about BPBIs and evidenced based beneficial therapeutic interventions, including consideration of the psychosocial aspects that may present over time as a result of having a BPBI. This program would be a secondary prevention program, with the outcome intended to improve the health of children with BPBIs at the group and population level.

The series of online educational modules on Brachial Plexus Birth Injuries (BPBI) this author developed was guided by the *Social Cognitive* (interpersonal) and *Community Engagement* (community) theories because the program is intended to be used by occupational and physical therapists, competent in the evaluation and treatment of children with BPBI, who are committed to being involved with developing and participation in a yearly online continuing education series with community providers. The main goals of the program are to increase community provider's knowledge, self-efficacy, and collaboration between with other community providers working in rural and underserved areas or with marginalized populations. An additional program goal is to advance community providers' knowledge and competency for treating children with BPBI, while building a supportive community network to ensure all children can reach their maximal potential. By addressing the goals listed above, this author hopes to decrease health inequities by increasing children's access to specialty care within their

local community.

Guiding interpersonal theory: Social cognitive theory

Social cognitive theory developed by Bandura (1986), is based on the belief that factors that can influence change may include an individual's personal and environmental factors and the idea that human behavior has a big influence over others' behavior. The program this author developed is intended to cultivate a safe learning environment where community providers increase their knowledge and confidence through participation in a group learning environment. Throughout the learning modules, learning activities are intended to increase the engagement of community providers with each other to increase self-efficacy through observational learning, reinforcement from peers as well as from learning from application of new knowledge in between learning modules. By including activities that need to be explored and some that need to be shared through a posting on the learning module website, we can increase one's behavioral capability and begin to address reciprocal determinism, so participants become more comfortable with practice and participation in mentoring with other community providers and advanced practitioners.

Guiding community level theory: Community Engagement

The second guiding theory this author selected was the *Community Engagement Theory* because the key concepts and principles include: Community Capacity, Empowerment, Critical Consciousness, Participation and Relevance as well as Health Equity. When applying community engagement theory, it is essential to assess the community's ability to identify key problems and engage the community to actively take

part in problem solving, how they might collaboratively approach, and address identified problems or concerns. By including community providers in the development of the program, this will empower providers to develop a structure and network with other community providers for ongoing support. Therefore, the first step in the development of this series of online learning modules, this author conducted a *Community Provider Feedback survey regarding BPBIs* in July 2020. This author sent an introductory email with a link to Early Intervention Program Directors and OT and PT providers in all New England states. This author also randomly sent the same email with the survey link to occupational and physical therapy providers in the Early Intervention network in New York. The survey clearly outlined the rationale for the survey was to use their feedback for the development of the actual online educational series, to ensure community providers understood the course would be relevant to their needs. This author submitted the survey to the Institutional Review Board (IRB) at Boston University to determine if it would require IRB oversight, and the BU IRB determined it was exempt.

Keeping community engagement in mind, one of the primary goals when developing the series of online educational modules, was to develop greater collaboration between community providers as this will allow for ongoing mentorship between providers when support is needed. This strategy was found to be effective by collaborations between community providers and subspecialists in several studies found in the literature (Ashburner et al., 2016; Bywood et al., 2013; Careau et al., 2008; Day et al., 2012; González-Espada et al., 2009; Mahnke et al., 2011; Shivji et al., 2011; Ray et al., 2015). Including didactic activities that require participants to collaborate and

problem solving with each other, will develop participants' ability to self-reflect and begin to develop their ability to mentor each other in a structured/safe environment. This has been found to be effective in coaching models outlined by several studies (Graham et al., 2009; Graham et al., 2013; Little et al., 2018; Mahoney et al., 2004; Siller & Sigman, 2002; Vismara et al., 2013; Wallisch et al., 2019). By developing these relationships during the online learning modules, the hope is this will sustain itself beyond the conclusion of the program.

Key findings this author gathered from the community provider survey (Appendix C) regarding Brachial Plexus Birth Injuries, revealed striking concerns around community provider knowledge as it relates to important milestones in healing for surgical and non-surgical interventions, which this author anecdotally anticipated. Results affirmed the desperate need to solicit support from important stakeholders as outlined in Figure 4.2. Even though 69% of community providers reported they had 16 to 47 years of practice experience, 63% of providers have only worked with 1-5 children with BPBI with an additional 13.2% reporting they had only worked with 6-10 children. Also, important to note as detailed in Figure 4.1, is only 19.1% of providers are 10 to 15 miles from a specialty provider, while 51.3% of providers are 25-50+ miles or more, with an additional 13.2% of providers reported they were not even certain of the distance to the closest specialty provider. These statistics highlight not only the potential burden distance may play in accessing specialty care for individuals, but also the barrier of community provider knowledge to deliver optimal care in rural areas. This supports the crucial need to increase community provider knowledge and access to collaborations,

tele-consultations, and online educational opportunities with subspecialists for timely and quality care of the pediatric population. This program aims to address important social and health justice for those children and families living in rural, underserved areas as well as those from marginalized populations.

Results from social/environmental survey

Figure 4.1 Distance to closest pediatric orthopedist or plastic surgeon

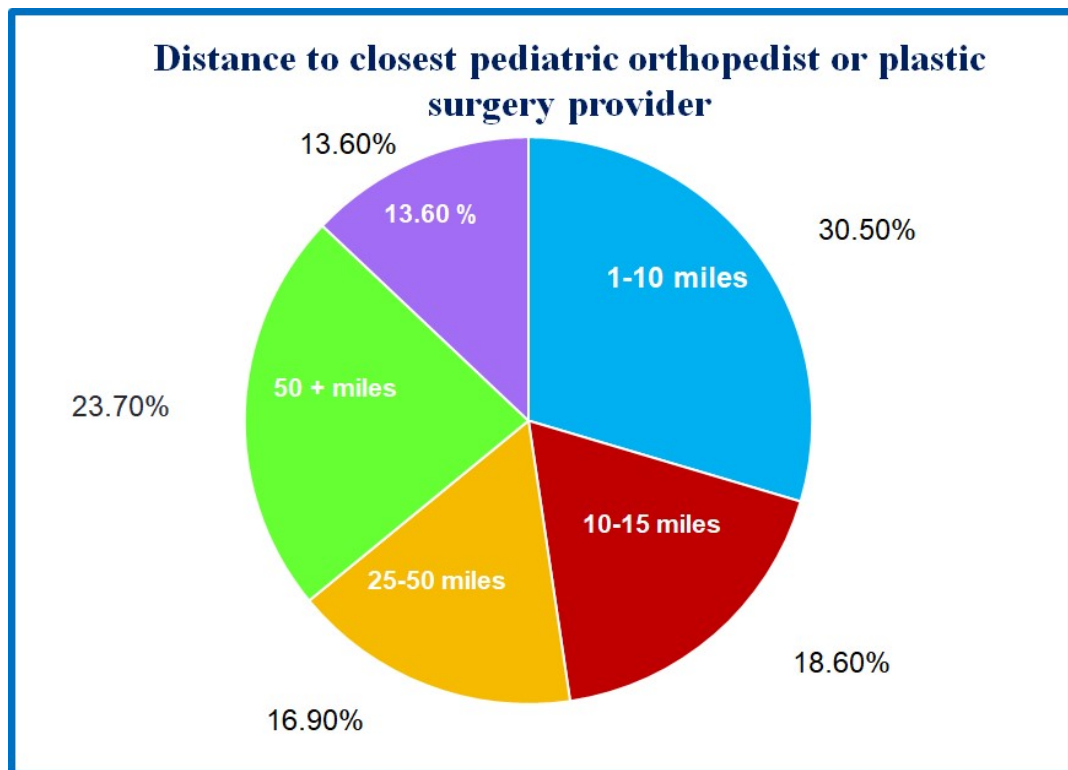


Figure 4.2 Community provider comfort/knowledge: Risks, causes assessment and important specialists

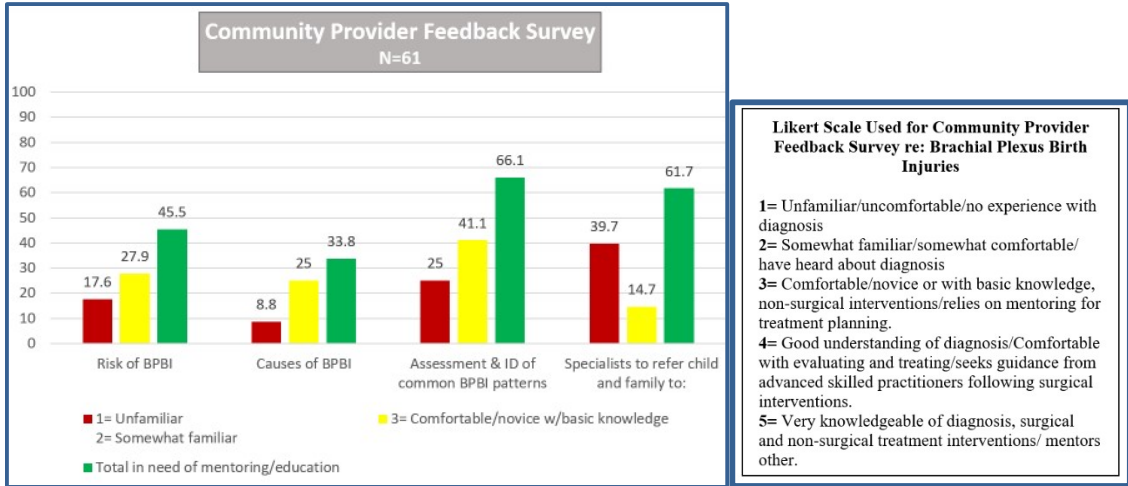


Figure 4.3 Community provider comfort/knowledge: Surgical and non-surgical interventions

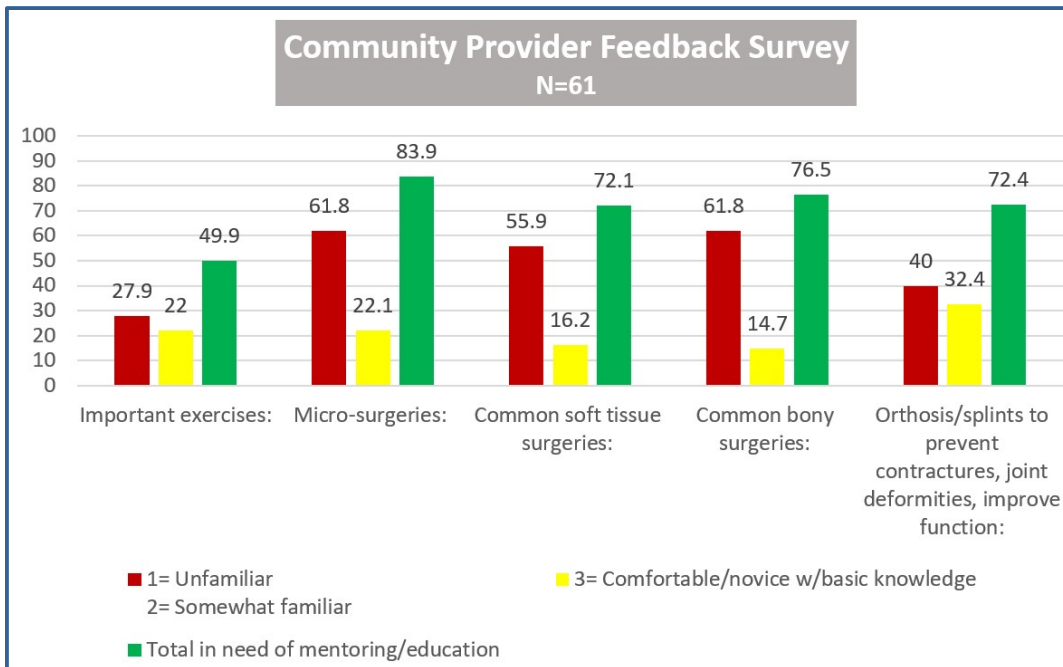


Figure 4.4 Community provider comfort/knowledge: Personal and environmental factors

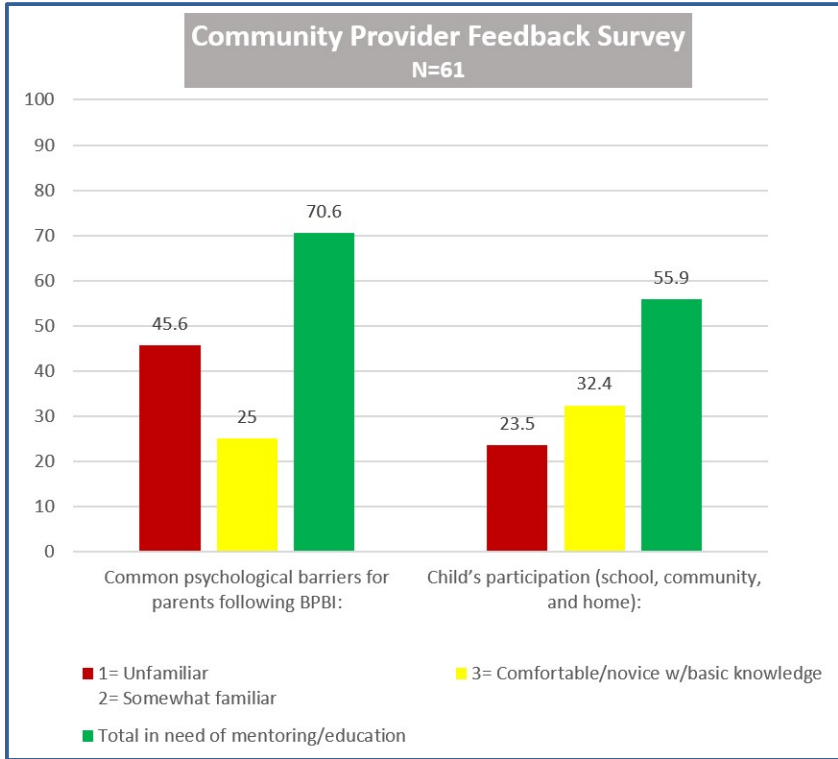


Table 4.1 Result of Social Survey from Community Provider Feedback Survey re: BPBI

% of respondents indicating need/benefit for mentoring/education (N=61)	Educational Topic
45%	Risks of BPBI
33.8%	Causes of BPBI
66.1 %	Assessment and identification of common BPBI patterns
61.7 %	Knowledge of appropriate specialists to refer children and families to.
49.9 %	Important exercises
72.1	Common soft tissue surgeries
76.5 %	Common Boney surgeries
72.4%	Orthosis/splints to prevent contractures, joint deformities or improve function
70.6%	Common psychological barriers for parents following BPBI
55.9%	Child's participation (school, community, and home).

Stakeholders

Key stakeholders this author identified as important to engage in the development and support of the program include stakeholders that will not only benefit from gaining of knowledge for evaluation and treatment of the BPBI population (community occupational and physical therapists), but also directors of community early intervention agencies, program directors at Boston Children's Hospital (BCH) in the departments of PT/OT, Department of Orthopedics, Office of Community Health, Office of Governmental Relations as well as the Marketing and informatics programs. By engaging these important stakeholders, the hope is that there will be greater support to promote this type of programming to better meet the needs of children, families, and isolated community providers to address health and social inequities in rural or underserved areas. This author's hope is that through engagement of these important stakeholders there will be greater awareness of these health disparities and that this program can serve as a model for future community-based programs to address population health at a macro community level.

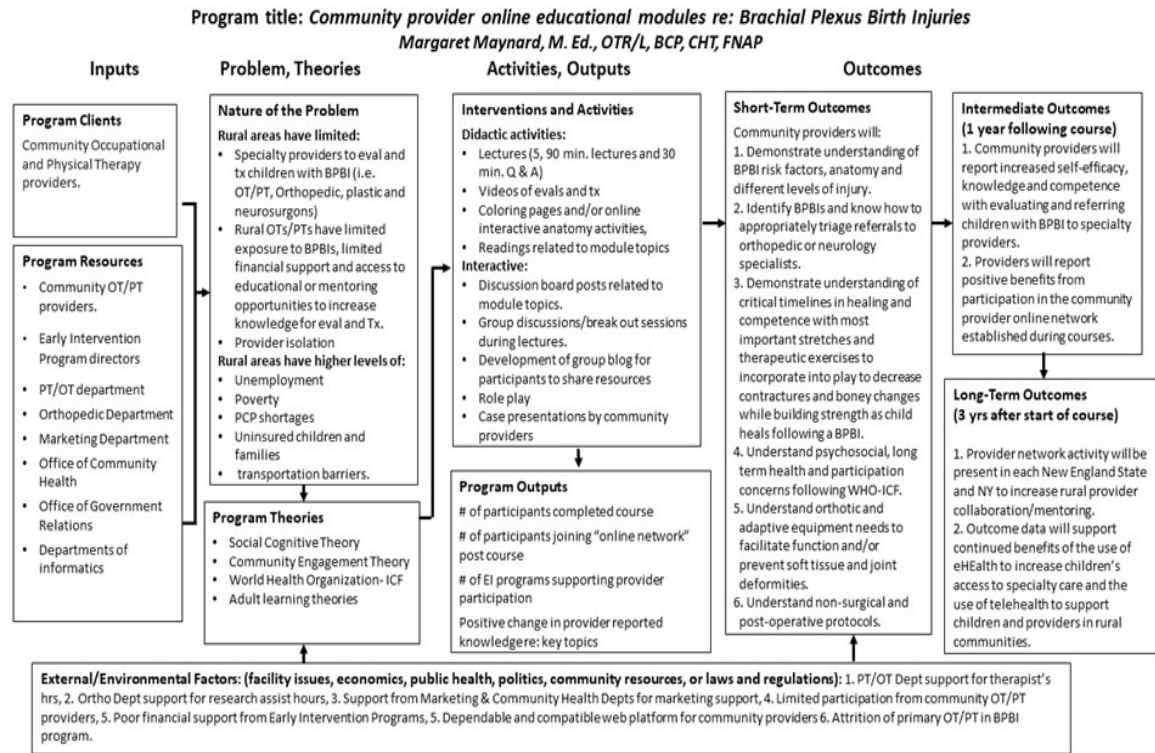
In this author's experience, working in pediatric academic medical centers, in homes while working in Early Intervention as well as in northern New England, I have seen the burden poverty and rural resource poor areas place on families that do not have the resources, knowledge or support to access specialty care if it requires driving longer distances. Children in these areas often do not have timely diagnosis during critical windows in the healing and growing process when they may benefit from available microsurgeries, bony, and soft tissue interventions to prevent greater disability in the

affected limb. When community pediatricians, community occupational and physical therapists have little knowledge of this diagnosis, there is greater potential for missed opportunities.

This author presents a full logic model (Figure 4.5) for the Brachial Plexus Birth Injuries: Community provider learning modules to be used with community providers interested in learning more about evaluation and treatment of Brachial Plexus Birth Injuries. The logic model (Figure 4.5) developed is also intended to be utilized as a blueprint to clearly outline the intended participants of the program, program resources, the problems that this program is intended to mitigate as well as the foundational theories that this program was built on. Given this author's research on the need for specialists to better support community provider's acquisition of knowledge and competence with working with this patient population and the most effective components of tele-educational programs (Ashburner et al., 2016; Bywood et al., 2013; Careau et al., 2008; Day et al., 2012; González-Espada et al., 2009; Mahnke et al., 2011; Shivji et al., 2011; Ray et al., 2015), this author has designed the online educational program to include as many active and reflective learning activities to meet the needs of adult learners, while including interactive group activities to build relationships between community providers to increase their support "network" (González-Espada et al., 2009; Hall-Barrow, et al., 2009; Shivji et al., 2011; Ray et al., 2015). This full logic model is intended to be a dynamic document to meet the needs of the program clients each year, based on program evaluation feedback and most importantly, modified as deemed necessary through review of current evidence on clinical practice and evidence gathered through research. A full-

size version of this logic model is available in Appendix A.

Figure 4.5 Full Logic Model



Program participants and resources

The primary personnel who will carry out the programming will be occupational and physical therapists on the Boston Children's Hospital Physical and Occupational Therapy Department's Brachial Plexus (BP) subcommittee. The BP subcommittee will keep up-to-date literature and evidence related to evaluation and treatment planning, post-operative guidelines in collaboration with the Boston Children's Brachial Plexus Team. The BP subcommittee will also organize conference mailings and flyers and solicit speakers from the orthopedics department, and community physical and occupational therapists that have close affiliations with the Brachial Plexus Team at BCH for the once-a-year online learning modules.

Funding for the primary Occupational and Physical Therapist from the Brachial Plexus Program will be supported by the PT/OT Department and Department of Orthopedics for administrative time each year to (1) prepare, facilitate, and support the online learning modules during sessions and (2) allocate an additional 2-3 hours for each module to answer questions and facilitate discussion boards as needed.

Administrative Considerations

The primary occupational and physical therapists in the BCH Brachial Plexus Program will be responsible for continual review of program activities and resources used in the program to ensure the program uses the most up-to-date evidence related to areas covered in the online program modules. The primary OT and PT will also be responsible for seeking ongoing physician, occupational therapy and physical therapy provider engagement in teaching of modules. The primary OT and PT in the BP program will also present educational sessions during the online modules, provide, and monitor didactic activities, supplying support to participants during course as needed. These individual therapists will also facilitate discussions during online modules and discussion boards and upload recorded presentations for online learning modules for participant's review.

The BCH PT/OT department's Brachial Plexus subcommittee will handle identification and distribution of emails and flyers to early intervention agencies in New England and mid-Atlantic states, in collaboration with the marketing department. In collaboration with the marketing and informatic department, the primary OT and PT in the BP program will develop and manage a website for the online modules as well as resources for frequently asked questions and references related to content presented in

modules.

Interventions and Activities

This online program takes into strong consideration adult learning theories (Knowles, 1980) as well as key ingredients from previously developed successful tele-education programs to support community providers acquisition of knowledge and competence. This author plans to have both didactic and interactive activities included in the program. Examples of didactic activities in the program will include 90-minute lectures followed by 30 minutes of question and answers. Lectures will include videos of evaluations and treatment interventions, provision of coloring pages and/or online interactive anatomy activities, in addition to readings related to module topics. The interactive components will be inclusive, but not limited to, discussion board posts related to module topics. Lectures will include group discussions and breakout sessions when appropriate. There will also be development of a group blog for participants to share resources, opportunities for role playing to provide opportunities for therapists to build confidence and self-efficacy for difficult conversations with providers and families. There will also be opportunities for providers to present case studies to the group to increase collaboration and critical thinking. See the program manual in Appendix B for week-by-week topics and learning activities.

Program outputs and outcomes

Program outputs that will be measured as part of the evaluation plan include the number of participants that successfully complete the online course, the number of participants joining the “online network” following participation in the course in addition

to the number of Early Intervention programs that support provider participation.

Short-term outcomes that the program hopes to achieve at the conclusion of the course are as follows.

Community providers will:

1. Demonstrate understanding of BPBI risk factors, anatomy, and different levels of injury.
2. Identify BPBIs and know how to appropriately triage referrals to orthopedic or neurology specialists.
3. Demonstrate understanding of critical timelines in healing and competence with most important stretches and therapeutic exercises to incorporate into play to decrease contractures and boney changes while building strength as child heals following a BPBI.
4. Understand psychosocial, long-term health and participation concerns following WHO-ICF.
5. Understand orthotic and adaptive equipment needs to facilitate function and/or prevent soft tissue and joint deformities.
6. Understand non-surgical and post-operative protocols.

Intermediate and long-term goals will be assessed 1 year and 3 years through follow up emails to participants with an online survey link included. **Intermediate outcomes** that will be evaluated 1 year following conclusion of the course, to assess if community providers report increased self-efficacy, knowledge, and competence with evaluating and referring children with BPBI to specialty providers. Secondly, we will

study if providers report positive benefits from participation in the community provider online network established during courses.

One long-term outcome that is hoped to be achieved by 3 years after the start of the course is that there will be an active community provider network in each New England state and New York to increase rural provider collaboration/mentoring. **The second long-term goal** is that outcome data will support continued benefits of the use of eHealth to increase children's access to specialty care and the use of telehealth to support children and providers in rural communities.

Anticipated barriers and challenges of implementation

The world of healthcare is an ever-changing entity as we have most recently seen with the COVID-19 pandemic. Fluctuating revenues and budgets within departments, states, and community programs, have required this author to closely consider barriers and challenges for successful implementation and follow through of this program (Figure 4.6). This author expects that there will need to be consistent support from the PT/OT department each year to consistently allocate funds for the primary occupational and physical therapist's time away from patient care, unless revenue from putting the course on off-sets the cost of the OT and PT's participation during online modules. It is also felt that it would be most beneficial to have a large enough attendance each year to support the creation and "sense of community" for providers. To fulfil the goal of increasing collaboration between community providers and specialists, it is essential that there is consistent participation from the orthopedic physicians, nurse practitioners and physician assistants in the lectures. It will also be essential for the PT/OT department and the

Orthopedics department to provide ongoing financial support for a research assistant's hours to compile data from surveys to ensure evaluation feedback is analyzed properly.

Other aspects of the program that could be potential barriers is ongoing support from the BCH Marketing & Community Health Departments so that marketing of the program reaches the greatest number of stakeholders as possible. These departments will also play an essential role in messaging the goal of the program is to decrease health disparities for children and families so that community providers can gain the financial support from the Early Intervention Programs for community provider's participation.

This author has also considered the fact that many rural communities do not have dependable broadband internet and that many community providers may not have compatible web platforms for effective delivery of the live lectures; therefore, it will be essential for the program administrators to work closely with the informatics team to optimize the web-based platform for participants.

The last anticipated barrier or challenge that this program needs to consider each year is the potential for attrition of the primary OT/PT in the BCH BP program; therefore, it will be essential to continually include and train additional therapists not only for participation in the online learning modules, but in the BCH Brachial Plexus program to build knowledge and competence so that the program can continue with a high level of expertise.

Figure 4.6 SWOT Brachial Plexus Birth Injuries: Community provider online learning modules

	Helpful To achieve objective	Harmful To achieve objectives
Internal Origin Attributes of the organization	<p>Strengths:</p> <ul style="list-style-type: none"> Expert specialty physicians and OT/PTs dedicated to BPBI population. Commitment of BCH, PT/OT, and Orthopedics departments to conduct research, education and community outreach. BCH commitment of health equity 	<p>Weakness:</p> <ul style="list-style-type: none"> Yearly budget/commitment of PT/OT & Ortho departments Consistent support from department each year to allocate time away from patient care unless revenue from putting course on off-sets OT/PT participation during online modules. Time allocation for consistent review of literature and evidence by BP subcommittee. Consistent review and modifications to post-operative protocols. Attrition of BCH staff Orthopedics Department participation in lectures and support for research assist hours to compile data from surveys.
External Origin Attributes of the environment	<p>Opportunities:</p> <ul style="list-style-type: none"> Collaborations with EI OT/PT providers for participation in course and presentations. Collaborations with other expert OT/PTs and physicians working/collaborating with BCP BP team to participate in course. Collaborations with states for funding for Early Intervention provider's attendance. 	<p>Threats:</p> <ul style="list-style-type: none"> Large enough attendance each year to support the creation and sense of community for providers. Participation of outside specialty providers in program Financial support from Early Intervention Programs to support community provider's participation. Dependable and compatible web platform for community providers.

Summary and conclusions

As is outlined throughout this program description, the community provider online educational modules have been developed based on other successful eHealth collaborations between specialists and community providers to address the health disparities for individuals living in rural or underserved areas of the country. This program has intentionally drawn from the evidence gathered in the literature from community provider's experiences regarding what types of learning activities were the

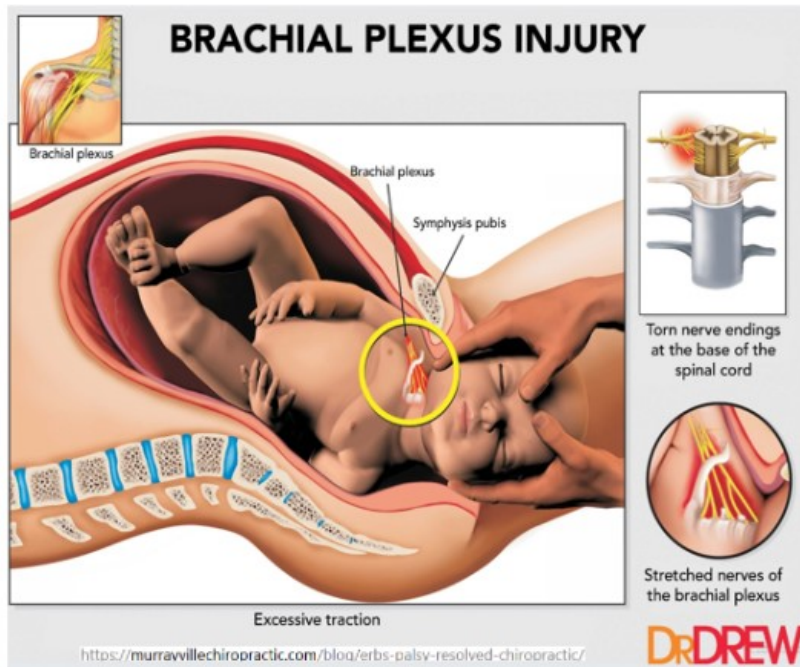
most helpful in building knowledge and competence for everyday practice. In addition, this author was intentional in grounding program content and activities based on the social cognitive theory and adult learning theories following analysis of data gathered from a Community Provider Feedback Survey as a means for engaging the community in the development of the program itself. It is the hope that outcomes from the program will assist this author in modifications and further development of programming not only for this pediatric population, but that the program may serve as a model for future development of other programs to build community provider's knowledge, competence, and support network to meet the needs of children in rural and underserved areas.

CHAPTER FIVE – Program Evaluation Research Plan

Program Scenario and Stakeholders

This doctoral project is intended to address health inequities and disparities for children living in rural and underserved areas as well as for marginalized populations, where access to specialty care is limited. The literature shows that families in rural areas have poor access to specialty care for many socio-economic, personal, and environmental factors in addition to provider shortages (Arora et al, 2011; Callas, 2000; Jackson et al., 2008). Community occupational therapy (OT) and physical therapy (PT) providers in rural areas also face barriers with managing and treating children with complex medical needs due to poor access to continuing education and specialty provider support. Understanding the importance of community engagement in the development of programming to support changes at the community level, I collected information from community OT and PT providers, about their experience, knowledge and comfort with treating and address specific topics related to Brachial Plexus Birth Injuries (BPBI). Brachial Plexus Birth injuries (BPBI) occur 1/1000 births and are a result of excessive traction on a child's neck when the child's shoulder gets caught on the mother's pubic bone during the delivery process (Figure 5.1).

Figure 5.1 Mechanism of Brachial Plexus Birth Injuries



The nerves that come from the spinal cord and power the muscles in the arm are damaged, with the potential of 10%-18% of injuries being permanent (Chauhan, S. et al., 2014; Frade et al., 2019). The survey allowed providers to check boxes or provide free text in “other” to indicate what they would like to know more about related to treatment of the BPBI population. The program I am developing is called “Brachial Plexus Birth Injuries Community Provider Learning Modules”. The program consists of 5 live, online learning educational modules, which will also be recorded for review by participants enrolled in the course, and the course will be offered one time per year. This course will include didactic activities to be completed independently and in collaboration with other participants. In addition, participants will also take part in weekly online “blackboard” discussions to build the community provider network for collaboration and mentoring. Details of each of the modules may be seen in Appendix B.

Program Participants, Facilitators and Program Delivery

Community occupational and physical therapists are the priority population for participation in the online learning program. The live sessions will be taught by this author, primary OT in the Boston Children's Hospital's (BCH) Brachial Plexus Clinic at Boston Children's Hospital, the primary PT in the BCH BP Program, and Orthopedic surgeons from BCH. Guest OT and PT providers from collaborating institutions, with advanced knowledge about BPBIs, will also be invited to present on specific topics each year. The delivery of the course content will be on-line with 5 live sessions, which will be recorded for the participants to review independently.

Key Stakeholders for Program Evaluation Results

Several key stakeholders this author identified as important participants are outlined below.

- **Community occupational and physical therapist:** To highlight positive outcomes and participants' feedback on the effectiveness of learning platform and activities as well as participants' reported gains in knowledge, comfort, and self-efficacy after participation in the program.
- **The Physical Therapy/Occupational Therapy Department Director:** To gain direct support for the primary occupational therapist's hours during the 6 online learning modules (1.5 hrs. each) as well as 2 hr. per week to monitor and respond to discussion boards during the 6 weeks of the course.
- **The Boston Children's Orthopedics Department/ Brachial Plexus Team:** To provide support/participation in 1-2 lectures related to surgical and non-surgical

content to increase understanding and collaboration between surgeons and community providers.

- **Boston Children’s Hospital Marketing Department** to provide additional financial and consultation support for OT hours related to marketing and advertising throughout New England and NY.
- **Boston Children’s Hospital Governmental Relations Department** will also be included to increase awareness and study the effectiveness and benefits of this community outreach program to further support their advocacy for telehealth legislation for children across state lines.
- **Key stakeholders in the Office of Community Health.**
- **Individual state Medicaid and Early Intervention Program Directors** to increase financial support for community provider’s course fees.

Vision for the Program Evaluation Research

The program evaluation for *Brachial Plexus Birth Injuries: Community provider educational modules* is intended to explore the potential benefits this type of online program may have in increasing children’s access to specialty care living in rural areas through the participation of community OT and PT providers in the online educational modules, which will be delivered by specialty providers at a pediatric academic medical institution. A second intention is to build a network of community providers working in rural communities where the literature shows children and families are at greater risk of poor access to OTs and PTs due to provider shortages.

The program is meant to address the financial barriers community therapists face for

accessing continuing education and/or mentoring so that they can appropriately and confidently care for children with complex medical conditions. This program aims to decrease rural provider isolation, increase provider knowledge, competence, and self-efficacy, while increasing their access to resources. Positive outcomes from this program could serve as a model for the development of similar programs for a variety of patient populations or rare conditions. Currently, the Boston Children's Hospital is committed to community outreach in the local Boston area as well as in other parts of New England where medical institutions may not have pediatric physician specialists. I believe this is an opportunity for pediatric Occupational and Physical Therapists to begin to advocate for equal support of community allied health providers, particularly in rural or underserved areas. The literature has shown it is important to decrease rural provider isolation by increasing collaborations and networks, so community providers have the ability to integrate knowledge and application of knowledge for the betterment of the children and families they serve (Arora et al, 2011; Callas, 2000; Jackson et al., 2008). This evaluation will study if the proposed program is effective at decreasing provider isolation both in the short term (post course) as well as in the long term (1 & 3 yrs post course). The course evaluation will also study if community providers report they have greater knowledge and comfort with treating children with BPBI, which then ultimately increases children's access to specialty care and further supports the positive benefits of this type of community OT/PT provider learning format.

Engagement of Stakeholders

In order to increase community occupational and physical therapy provider's knowledge, competence and confidence in treating BPBIs, the following stakeholders have been identified as crucial to the development, promotion and implementation of the program. In designing the program, a preliminary social assessment was conducted with the priority population, community OTs/PTs, to better understand what their needs were in relation to education on a variety of important topics specific to this population. This was done using an online survey, (see Appendix C) which was emailed to Early Intervention Directors, EI OTs/PTs in New England and parts of NY in addition to posting the online link on the Community Provider Feedback Survey re: Brachial Plexus Birth Injuries.

Other key stakeholders to be included:

- **Early Intervention Program directors in New England and NY:** To help with marketing of the program to community providers and financial support of community providers.
- **Boston Children's Hospital PT/OT Department Director:** To support the lead OT/PT in Brachial Plexus Program 5-10 hrs./yr. to develop content and learning activities and additional OT/PT hrs. to present program and manage online learning activities (2 hrs. X 5 modules + 2 hrs. for facilitating blackboard discussions: total 20 hrs./yr.)
- **Boston Children's Hospital Orthopedic Department:** The Chief of Orthopedics at Boston Children's Hospital is an upper extremity surgeon and a primary provider on

the Brachial Plexus Team at BCH. He is also engaged internationally and nationally with surgeons, scientists, researchers, and specialty providers to optimize outcomes for children with BPBI. The Chief of Orthopedics and three other orthopedic upper extremity specialists on the Brachial Plexus team have expressed commitment to increasing community providers knowledge on this condition by developing a conference for the New England and mid-Atlantic states because patient outcomes are directly affected by their access to occupational and physical therapy services.

Research will be presented related to barriers children, families, and rural community providers face in addition to highlighting the results from the “Community Provider Feedback Survey re: BPBI” to the orthopedic physician’s, highlighting the need to engage them in direct participation in lectures, and provision of support for a research assistant’s time for collection and analysis of data for program evaluation.

- **Boston Children’s Hospital Marketing Department and Office of Community Health:** Engagement of these two offices for assistance of one employee, 1X/year, will be essential to develop and modify a list serve or distribution list, for marketing of the program to pediatricians and Early Intervention Programs throughout New England and NY. The Office of Community Health’s mission, which is in alignment with the mission of the hospital and my program to decrease health inequities, will allow this program to be evaluated and assessed to see if this could serve as a model for implementation of similar community provider education programs for different complex medical conditions.

- **Boston Children’s Hospital Office of Government Relations:** In direct alignment with funding to support eHealth programming to promote health equity/ justice for children and families in rural or underserved areas.

Detailed results of this preliminary inquiry were discussed in Chapter 4, but to briefly review, the (N=61) percentage of respondents that indicated they would need/benefit from additional mentoring and education for proper evaluation and treatment of BPBIs is as follows:

Table 5.1 Result of Social Survey from Community Provider Feedback Survey re: BPBI

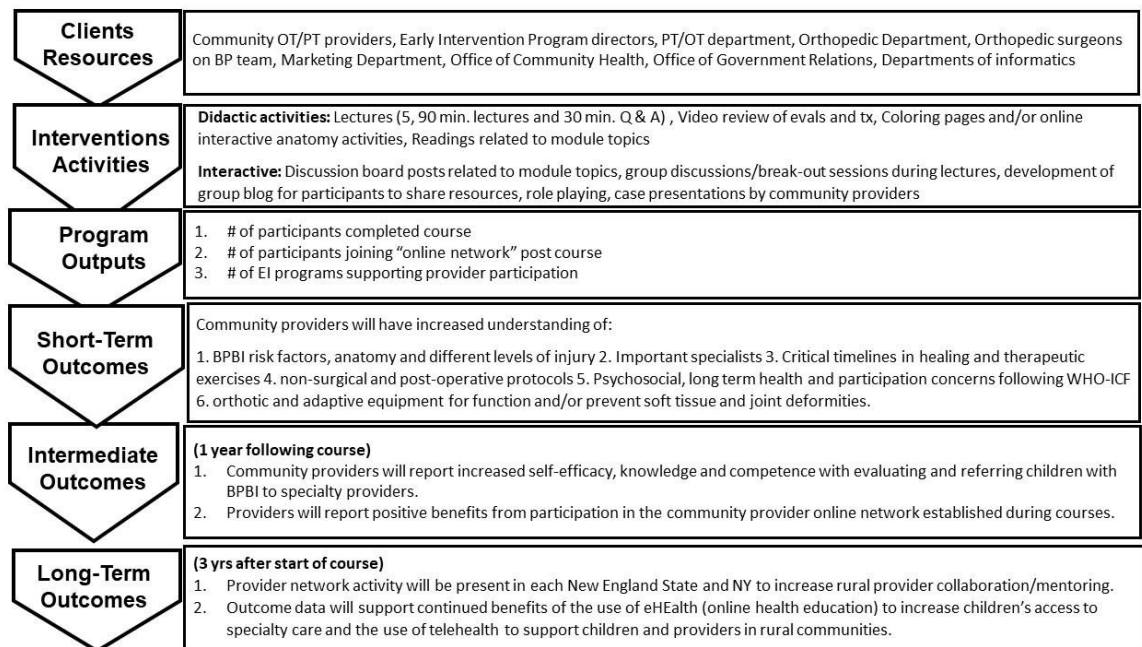
% of respondents indicating need/benefit for mentoring/education (N=61)	Educational Topic
45%	Risks of BPBI
33.8%	Causes of BPBI
66.1 %	Assessment and identification of common BPBI patterns
61.7 %	Knowledge of appropriate specialists to refer children and families to.
49.9 %	Important exercises
72.1	Common soft tissue surgeries
76.5 %	Common Boney surgeries
72.4%	Orthosis/splints to prevent contractures, joint deformities or improve function
70.6%	Common psychological barriers for parents following BPBI
55.9%	Child’s participation (school, community, and home).

Simplified Logic Model for Use with Stakeholders

The simplified logic model for the *Brachial Plexus Birth Injuries: Community provider educational modules* (Figure 5.1) outlines the intended stakeholders as well as intervention activities to address gaps in services and knowledge that individuals face while working and living in rural communities. Program outputs, short term, intermediate and long-term outcomes to be measured will attempt to answer questions about feasibility, effectiveness, and potential use of this type of eHealth with a variety of community providers serving a variety of pediatric patient populations. The simplified

logic model (5.1) will be an important part of the evaluation plan to determine which aspects of the program are successful in meeting the program's short- and long-term goals.

Figure 5.2 Simplified logic model of BPBI: Community provider educational modules



Preliminary Exploration and Confirmatory Process

This author's preliminary exploration and confirmatory process will begin with a meeting with the Boston Children's Upper Extremity Hand Team to present key findings from the preliminary Community Provider Feedback Survey and discuss how findings are consistent with existing literature reviewed by this author on barriers children and families in rural areas face in a short PowerPoint, including references for future review by individual stakeholders. In addition, the author will present findings and discuss the barriers OTs and PTs face related to the use of telehealth, including legislative and professional licensure rules and the impact on community provider's development, which

ultimately impacts patient outcomes.

During this author's presentation of survey findings, the author will emphasize how this program could serve as an innovative model for the rest of the nation to address health equity issues children and families face in rural areas. Presentation to the stakeholders will highlight how the program is intended to increase children's access to specialty care at a secondary prevention level by increasing community provider knowledge. This will be especially highlighted to get buy in from the Office of Community Health and Office of Governmental Relations, as both are fierce advocates for policy changes to increase health equity.

Program evaluation research questions (Table 5.1) are intended to provide both quantitative and qualitative outcomes pertinent to all stakeholders for ongoing support of this program.

Table 5.2 Program Evaluation Research Questions by Stakeholder Group

Stakeholder or Stakeholder Group	Types of Program Evaluation Research Questions
<ul style="list-style-type: none"> - Community OT/PT providers - This primary researcher (OT) - Boston Children's Hospital PT/OT Department Director - BCH Chief of Orthopedics - BCH Brachial Plexus Team 	<p>Quantitative:</p> <ul style="list-style-type: none"> ● Do community providers report increased self-efficacy, knowledge, and competence with evaluating, treating and referring children with BPBI to specialty providers? (pre-post course survey) <i>Likert scale</i> ● Was the course length adequate for meeting objectives of the course and learning? <i>Likert scale</i> ● Was the content presented too advanced? ● Did participants report knowledge gained could easily be applied to their practice? <i>Likert scale</i> ● Was the cost of the course reasonable? <i>Likert scale</i> <p>Qualitative:</p> <ul style="list-style-type: none"> ● Do community providers feel the live presentations online were more, or less beneficial, than reviewing recorded presentations? <i>Open-ended questions</i>

	<ul style="list-style-type: none"> ● Do community providers feel the didactic activities of the course (blackboard discussion, small group activities, supplemental coloring, and interactive activities) increased their understanding of the content? <i>Open-ended questions</i> ● Which activities supported participants' learning best? <i>Open-ended questions</i> ● Do community providers report positive benefits from participation in the community provider online network established during courses? <i>Open-ended questions</i> ● Do community providers report the online learning program was easy to participate in through the online platform? <i>Open-ended questions</i> ● Do community providers report an increased sense of community through the online network established during the course? <i>Open-ended questions</i> ● What changes to the course would participants recommend? <i>Open-ended questions</i>
<p>-This primary researcher (OT)</p> <p>-PT/OT Dept. Director BCH</p> <p>-Chief of Orthopedics -BP Team</p> <p>-BCH Office of Community Health</p> <p>-BCH Office of Government Relations</p>	<p>Qualitative:</p> <ul style="list-style-type: none"> ● Has the course helped to develop provider engagement in a community provider network in each New England State and NY to increase rural provider collaboration and mentoring? ● Do the outcome data support positive benefits of the use of eHealth (specialty provider education of community providers) to increase children's access to specialty care and increased community provider competence with supporting children and families in rural communities? ● What changes to the course would participants recommend? <p>Quantitative:</p> <ul style="list-style-type: none"> ● Do community providers report increased self-efficacy, knowledge, and competence with evaluating, treating and referring children with BPBI to specialty providers? ● Did the Primary OT and PT feel they had adequate time to develop the program and manage online learning activities with outlined hours? ● Was there sufficient allocated time for the research assistant and primary OT/PT dedicated time to review and compile data for program evaluation? ● Did providers report high satisfaction with the return on investment in the program?

Research Design

The program will use a combination of Formative (qualitative) and Summative (quantitative) research designs (See Appendix C Formative and Appendix D Summative). Survey questions will include a combination of short answers, Likert Scales, open-ended questions, and a checklist for topics of interest, to provide program developers needed information prior to the development of the online learning modules to meet the needs of community Occupational and Physical Therapy providers. The same survey, using Likert Scales (quantitative) will be utilized immediately following the program in a post-course survey to measure the same dependent variables, including degree of change in participants' reported knowledge level/comfort level with key topics outlined in the pre-course survey. In addition, qualitative questions will be asked to analyze participant's feedback on open-ended questions about the online resources and community network. The follow-up feedback surveys at 1 year and 3 years, are intended to assess participant's maintenance of knowledge and comfort with evaluation, treatment interventions, with the addition of open-ended questions to post course surveys to capture qualitative data. For example, open-ended questions will investigate if participants feel the course has enabled development of provider engagement in a community provider network in each New England State and NY to increase rural provider collaboration/mentoring (See Appendix Table 2). Questions will explore if the outcome data supports positive benefits of the use of eHealth (specialty provider education to community providers) to increase children's access to specialty care through increased community provider competence to support children and families in rural communities.

SPSS software will be used to further investigate common themes from qualitative data. All open-ended responses will also be reviewed by the program coordinator (this author and primary occupational therapist in Brachial Plexus Clinic), primary physical therapist in BP clinic as well as the research assistant to triangulate results.

Approaches you might use to enhance the rigor of your analysis:

To improve efficiency with inputting of data and decrease potential for human error, this author will utilize REDCap surveys as well as NVivo for all open-ended responses to study common themes. All open-ended responses will also be reviewed by the program coordinator (this author and primary occupational therapist in Brachial Plexus Clinic), primary physical therapists in BP clinic as well as the research assistant to triangulate results.

Methods

Data Collection, Analysis and Storage.

To appropriately prepare for solicitation of participants, this author submitted the preliminary Community Provider Feedback Survey for review to Boston University's Institutional Review Board and was advised that this survey is exempt from needing an IRB approval. Researchers seek IRB review and approval to ensure individuals' rights and the welfare of human subjects are protected during clinic research and that research activity is conducted according to federal regulation, state law, and IRB policies. Additionally, the program's survey will also be submitted to the Boston Children's Hospital IRB if the program plan gains support by the stakeholders. REDCap will be

utilized for the Community Provider Feedback Survey. The program will utilize the same Community Provider Survey with each community provider enrolled in the course prior to the start of program and directly at the conclusion of the program to gather summative data to measure the change in participant's knowledge on the topics outlined in the survey, as a result of direct participation in the program. The post course survey data will be collected from participants and data will be analyzed using SPSS to allow data to be analyzed in a variety of ways, including cluster analysis, regressions, Chi-Square tests. Formative data regarding the course itself and impact on participant's learning and acquisition of knowledge will be gathered through open-ended questions as well as with a Likert Scale. Data will be analyzed through software such as NVivo using coding as well as through SPSS software to analyze quantitative data gathered. Data will be stored on an encrypted shared drive at BCH. This author will request additional support from the Orthopedics and Physical and Occupational Therapy Departments in addition to applying for additional grant funding to support allocation of a research assistant to assist with processing of data and analyzing results.

In conclusion, based on the preliminary data gathered in the Community Provider Feedback Survey conducted by this author, the program evaluation outlined will be essential to determine if components of the program design adequately meet the learning needs of the community providers so modifications can efficiently and effectively be made so that short, intermediate, and long terms goals can be met. This author's use of quantitative and qualitative program evaluation research questions is also intended to provide the needed relevant data to all stakeholders involved in supporting the program

financially or with personnel, to ensure ongoing assistance of this program.

CHAPTER SIX – Dissemination Plan

The dissemination plan for *The Brachial Plexus Birth Injuries: Community Provider Learning Modules* will require a methodical and comprehensive dissemination plan, given the key stakeholders have unique characteristics and connections to the program. The unique characteristics of the key stakeholders were considered when identifying the appropriate spokesperson to deliver the program messaging and program evaluation result. In addition, specific dissemination activities for key audiences and stakeholders were also considered and presented in this chapter.

Description of Program

The Brachial Plexus Birth Injuries: Community Provider Learning Modules is an online, interactive, and cost-effective educational platform to support community Occupational and Physical therapy providers with gaining knowledge and competency with evidenced based evaluation and treatment intervention for children with Brachial Plexus Birth Injuries (BPBI). This program includes lectures by Boston Children's Hospital's orthopedic hand surgeons, primary occupational and physical therapists from the Brachial Plexus Program at Boston Children's Hospital (BCH). The program also includes learning activities inclusive of reviewing current evidence in the research related to surgical and non-surgical treatment interventions, critical time frames in the recovery and healing phases following the birth injury and surgical interventions and the role of occupational therapy (OT) and physical therapy (PT). Additional learning opportunities involve online discussion boards and collaborative learning activities to cultivate the development of a community provider network, to better support families with a child

who has sustained a BPBI.

This author has developed this series of online educational modules on BPBI, considering the many social, economic and health disparities children and families in rural, underserved communities or in marginalized populations experience. The program is based on the positive outcomes reported in the literature regarding how telehealth, tele-educational and teleconsultations between subspecialists and community providers can increase knowledge and competence of the community provider and ability to care for children with complex medical conditions within their community (Ashburner et al., 2016; Bywood et al., 2013; Careau et al., 2008; Day et al., 2012; González-Espada et al., 2009; Mahnke et al., 2011; Shivji et al., 2011; Ray et al., 2015) . This program was also developed with adult learners' needs in mind for successful engagement in learning activities (Knowles, 1980).

Target Audience and Dissemination Goals

This author has identified several key audiences that will be targeted for dissemination of information regarding the *Brachial Plexus Birth Injuries: Community Provider Learning Modules*. The primary audiences include community occupational and physical therapists working with children with Brachial Plexus Birth Injuries as well as Early Intervention program directors, to increase their awareness of BPBI and the significant gap in access to specialty care and how participation in the program will provide positive benefits to OTs and PTs participating in this educational program to expand their knowledge and expertise for children they are serving in their communities. The dissemination plan will also include advertising of the program to state OT

associations in addition to advertising the program on American Occupational Therapy Association (AOTA) Community forums and in the OT Practice Magazine. In addition, the program will be marketed to the Pediatric Special Interest Section associated with AOTA to expand the reach to a larger number of OTs.

Secondary audiences that will be targeted to receive key messaging of the results of the program evaluation outcomes include the PT/OT department director, Boston Children's Hospital Chief of orthopedics as well as BCH's brachial plexus team and BCH's Office of Community Health as many of these departments have been active in advocacy efforts during the COVID 19 pandemic and understand the disparities individuals in poverty face in accessing healthcare. This author also intends to present the program evaluation results to the Governmental Relations Department at BCH to increase awareness and study the effectiveness and benefits of this community outreach program to further support their advocacy for telehealth legislation for children across state lines.

Vision of program

Building a supportive network of community providers, will create a platform for ongoing knowledge translation and provider competency. By building stronger collaborations between specialty and community providers, we can increase the potential that the necessary expertise for the evaluation and treatment of children with BPBI will be more readily available to address the health inequities children and their families face in rural and underserved areas.

Mission of program

Increase community provider knowledge and competency for treating children with BPBI through a collaborative educational platform between specialty providers and community OTs and PTs in a series of live, online learning modules. Goals at the heart of the program to be met by community providers to better serve children with BPIs include:

1. Decrease the risk of soft tissue and bony deformities,
2. Reduce the risk of limited participation and socialization,
3. Decrease the risk of depression and obesity and
4. Decrease the risk for barriers in vocational opportunities for children with a BPBI.

Key messages

- **Community occupational and physical therapists:** Brachial Plexus Birth injuries occur 1/1000 births and when children are born to families in rural or underserved areas where there is a shortage of specialty care providers, it is essential for community providers to build knowledge and competence with evaluation and development of appropriate treatment interventions to optimize children's potential for recovery of strength and function in the affected limb. It is also essential that providers gain the necessary knowledge of which specialty providers they should collaborate and refer families to, to evaluate and monitor recovery. Given there are key milestones and essential windows of time in a child's recovery process when surgical interventions could maximize function, *The BPBI: Community provider education modules* will provide therapists the critical knowledge to best support

children and families. Program activities not only address physical body structure and function, but more importantly participation, psychological wellbeing of parents and children as well as long term potential for wellness and health and participation in desired vocations.

- **Early Intervention Program Directors/ Office of Community Health/ BCH Director of PT/OT Department and BCH Orthopedics Department/ Brachial Plexus Team:** In order to justify ongoing financial and personnel support of *The BPBI: Community Provider Education Modules*, it is extremely important to show these key stakeholders the return on investment, particularly as it relates to the health inequities children in rural areas face. Therefore, this author will include the vision and mission of the program along with program evaluation results.
- **The Governmental Relations Department at BCH:** To provide evidence of the health inequities that children and families face in rural and underserved areas face this author will present the program evaluation results to the Governmental Relations Department at BCH. The goal of including this audience is to increase awareness of the gap in access to specialty care and emphasize the beneficial impact this community outreach program can have, but also to seek their support in advocating for telehealth legislation for children across state lines to mitigate these inequities.

Sources/messengers

The primary spokesperson for delivering messaging to occupational and physical therapists as well as Early Intervention Program Directors will be Margaret Maynard, M. Ed., OTR/L, BCP, CHT FNAP. Margaret has worked in early intervention programs and

has personal experience working with children in rural areas and currently works as the OT “specialist” triaging and mentoring OTs and PTs working with children in rural areas in her current role on the Boston Children’s Hospital’s Brachial Plexus Team.

The primary spokesperson who will deliver results of the program to the department of orthopedics and the office of community health will be Dr. Andrea Bauer, one of the primary orthopedic surgeons on the Brachial Plexus team because she is very dedicated to the BPBI population and has experience with seeking grant funding for studies related to this population. She actively collaborates with the primary occupational and physical therapist in the BCH BP program in addition to OTs and PTs across the country to conduct research around health inequities for this population and impact on quality of life for the child and family.

Lastly, the presentation of the program results to the director of the department of PT/OT will be completed by Margaret Maynard, OT and Dr. Andrea Bauer to emphasize the importance of interprofessional educational programming, to meet community provider learning needs while expanding our provider network to meet the needs of children in rural area.

Dissemination Plan

The executive summary and program evaluation results will be disseminated to the key stakeholders identified early in the program development. The executive summary will be provided in written form, including tables and visual graphs when appropriate, to show demographics of participants, percent changes in knowledge and qualitative themes. The executive summary will include the background information on

the program, the epidemiology of the BPBI diagnosis, risk factors children and mothers face in rural environments, including barriers pregnant women face in accessing prenatal specialty care, and the impact of maternal health. This author will present data from pre and post course survey results as well as quantitative data and qualitative results to show outcomes of the program in addition to discussing recommendations for future modifications of the program based on program evaluation results.

Administrative Considerations

The primary occupational and physical therapists in the BCH Brachial Plexus Program will handle continual review of program activities and resources used in the program to ensure the program utilizes the most up-to-date evidence related to areas covered in the program modules. The primary OT and PT will also be responsible for soliciting ongoing physician, occupational therapy, and physical therapy provider engagement in teaching of modules. The primary OT and PT in the BP program will also present portions of the (5) educational sessions during the online modules, provide and monitor didactic activities, giving support to participants during the course as needed. These individual therapists will also facilitate discussions during online modules and discussion boards and upload recorded presentations for online learning modules for participant's review.

The BCH PT/OT department's Brachial Plexus subcommittee will be responsible for identification and distribution of emails and flyers to early intervention agencies in New England and mid-Atlantic states, in collaboration with the marketing department. In collaboration with the marketing and informatics department, the primary OT and PT in

the BP program will develop and manage a website for the online modules as well as resources for frequently asked questions and references related to content presented.

Dissemination of program evaluation activities

- **Community occupational and physical therapists:** To highlight positive outcomes and participants feedback on the effectiveness of the learning platform and activities used in *The BPBI: Community Provider Education Modules*, program evaluation results will be presented in a poster presentation at the American Occupational Therapy Conference, OT state conferences from participating states, as well as in the OT Practice journal so that community occupational therapists will be able to learn about the benefits of this program. Results will include changes in community provider's knowledge, satisfaction with content in program, feedback on learning activities, satisfaction with return on investment, and provider's change in self-efficacy. Also included in the dissemination will be participant's feedback regarding usability and accessibility of continuing education platform and whether participants felt the program met the goal of increasing a community provider support network as this may serve as a good model for future community provider programming.
- **Early Intervention Program Directors:** The executive summary report will be sent to Early Intervention Program Directors who might sponsor Early Intervention (EI) providers in the future. Results will highlight changes in community provider's knowledge, satisfaction with content in program, feedback on learning activities, satisfaction with return on investment as well as provider's change in self-efficacy. Also included in the dissemination will be participant's feedback regarding usability

and accessibility of continuing education platform and if participants reported the program met the goal of increasing a community provider support network as this may serve as a good model for future community provider programming.

- **The Physical Therapy/Occupational Therapy Department Director and The Boston Children's Orthopedics Department/ Brachial Plexus Team:** The executive summary will be presented in an in person or ZOOM meeting, though electronic copies of the report will be sent to stakeholders to supplement power point presentation for future reference when discussing funding. Result will highlight changes in community provider's knowledge level on important key topics related to BPBI, community provider's satisfaction with content and learning activities in the program, satisfaction with return on investment, and provider's change in self-efficacy. Additional provider feedback will be highlighted in regard to their experience with usability and accessibility of the continuing education platform as well as constructive feedback on learning activities and overall program. In addition to reviewing participant feedback, the primary occupational and physical therapists directly involved in the development, implementation, and management of the program, including administrative responsibilities of managing the ongoing research and data collection will present documentation of hours invested in the program itself each year. By doing this, consideration around appropriation of occupational or physical therapist's time and discussion regarding funding or research assistant hours can then be reviewed as a team.


- **Office of Community Health:** The executive summary report will be sent to both departments electronically with the request to meet virtually to discuss executive summary. This author will highlight the program's effectiveness in changing community provider's knowledge level on key topics, satisfaction with content in program, feedback on learning activities, satisfaction with return on investment and feedback regarding community provider's change in self-efficacy. Participant's feedback regarding the usability and accessibility of the continuing education platform will also be highlighted to plan for future educational collaborations between the academic medical institution and community providers to address health disparities for children and families living in rural or underserved areas of New England and New York. The program evaluation results are intended to potentially serve as a novel model in pediatric health care and community provider education.

Budget

This author will be soliciting initial funding for the program through the hospital to begin the process of marketing the program to identified stakeholders as described in Table 6.1. In Chapter 7, this author discusses and outlines the proposed budget for the program, though \$500 dollars is allocated to cover the cost of the program's collaboration with Boston Children's Hospital Marketing Department to develop professional looking advertisements, surveys, and support for registration of participants. The Marketing Department uses many different social media platforms, which will extend the reach of advertising of the program to potential participants. Marketing will include some statistics gathered from community provider social assessment survey when developing

the program to show the overall educational needs and potential benefits of participation in the BPBI: Community provider online learning modules.

Figure 6.1 Boston Children’s Hospital Continuing Medical Education Marketing Fee Schedule



Tier 3 Marketing Elements

Digital Promotion

- » Multi-tab landing page for online registration/payment
- » (2) promotional emails
- » Save the Date listing on CME e-newsletter

Direct Mail

- » (1) Save the Date postcard (7" x 5")


Internal Communications

- » Announcement scroll (Boston Children’s Today)

Collateral*

- » Evaluation/Presentation business cards
- » Name tags & lanyards

* Additional collateral available à la carte menu



\$500

9" w x 6" h Postcards
4/4 80# coated cardstock

Quantity	1,000	2,500	5,000	7,000
Est Price*	\$455	\$736	\$1,207	\$1,524
Fulfillment	\$194	\$269	\$452	\$499

*Estimated prices for printing and fulfillment. Fulfillment is NCOA 6 de-dupe list, inkjet & mail.

Table 6.1 Summary of marketing activities

Stakeholder name	Specific Information Needs	Project Interests	Role
	<i>Types and frequency of communication</i>	<i>Specific areas of interest and communication</i>	<i>Decision Maker, Collaborator, Participant, Consultant, Information Recipient</i>
Community OTs and PTs	Types: Emails to pediatric OTs/PTs	Acquisition of knowledge to improve understanding of condition and evidence-based approaches to evaluation and interventions for BPBI population.	Collaborator: Social Assessment to determine community provider’s needs.
NICU consortium members	Emails/Website posts to state OT associations Email to NICU consortium participants Frequency: 5 months prior to course, then reminder emails 2 times a	Establish a network of pediatric occupational and physical therapists. Establish relationships with Orthopedic	Participant/ Information Recipient: Online learning modules Consultant: After the first year, participation in program planning and/or presentations

	month for last 2 months	surgeons caring for children with BPBI.	
Early Intervention Program directors and PCPs	Types: Send Emails & Flyers to Early Intervention programs in New England and NY Frequency: 5 months prior to course, then reminder emails 2 times a month for last 2 months	Promote affordable continuing education to increase knowledge and competence with caring for children with BPBIs.	Collaborator: Social Assessment to determine community provider's needs.
BCH PT/OT director	Types: Informational planning emails and direct meetings Frequency: 1 time a year to assess and determine budget.	Support and Promote the PT/OT department's commitment to education and collaboration with community health providers in caring for children with complex conditions. Increase health equity for children in rural and underserved areas.	Collaborator/Consultant: Budget, programming, and marketing
BCH Orthopedics Dept./ Brachial Plexus Team	Types: In person program planning meeting then emails for subsequent coordination. Frequency: 1 time a year in person meeting to determine the program and assess/determine budget.	Support and Promote BCH Brachial plexus Program' commitment to education and collaboration with community health providers in caring for children with complex conditions. Increase provider knowledge to better support children and families with BPBI to decrease effects of BPBI on children.	Collaborator/ Consultant Educational programming, marketing, research Participant Educational modules Information Recipient Pre- and post-participant survey results.
BCH Marketing Dept.	Types:	Effectively and efficiently promote mission, vision and goals	Collaborator/ Consultant Marketing of educational program

	<p>Informational planning emails and direct meetings</p> <p>Frequency: 1-4 times a year to determine target audience and marketing strategy.</p>	of BCH and program offering.	Registration
BCH Office of Community Health	<p>Types: Emails and in person meetings to discuss the program and strategize around marketing.</p> <p>Frequency: 1-2 times a year meeting.</p>	<p>Expand BCH's role in decreasing health inequity issues.</p> <p>Increase community outreach through community provider collaborations.</p>	<p>Collaborator Marketing of educational program to identified areas of need</p> <p>Strategies to extend reach of program</p> <p>Participant Social determinants Funding resources for families.</p> <p>Consultant Programming</p>
BCH Governmental Relations Dept.	<p>Types/Frequency 1-2 times a year meeting.</p>	<p>Increase awareness of the multitude of barriers individuals face in accessing specialty care.</p> <p>Study the effectiveness and benefits of this community outreach program to increase advocacy for individual state Medicaid funding to support community provider education.</p> <p>Continue advocacy to pass telehealth legislation for children across state lines.</p>	<p>Collaborator/ Consultant</p> <p>Advocacy opportunities for community providers</p> <p>Information Recipient Pre- and post-participant survey results.</p>

Evaluation

The dissemination plan and activities outlined above will be evaluated after each year to determine if the methods developed were effective in delivering the message about the goals of the program to key stakeholders and which strategy was the most effective in obtaining participants. This will be completed by monitoring the number of registrants, feedback provided by participants when they register, asking them to indicate how they heard about the program and which method of advertising provided them with key information that made them want to take the course. By doing this, we can determine if the method of advertising was instrumental in getting the word out about the course, but also which platform was the most user friendly and which method of advertising had the most effective messaging on the benefits of the course.

Conclusion

The dissemination plan for this doctoral project is intended to provide the follow through this author feels is necessary to fulfill the theoretical foundation of the program, which is community engagement. The program evaluation will provide the feedback to all stakeholders involved in the project the results to answer key questions around community providers' needs, effectiveness of the educational platform, program design and ability to provide an avenue to effectively build a community provider network so that children living in rural areas have greater access to specialty care. It is essential that dissemination of the evaluation results be completed so that stakeholders understand the return on investment, remain engaged and most importantly, results provide stakeholders and program developers the opportunity to continue to modify the program, or develop

similarly designed programming for other childhood conditions to mitigate the health care inequities similar to children with BPBIs living in rural or underserved areas.

CHAPTER SEVEN – Funding Plan

Introduction

This Brachial Plexus Birth Injuries: Community provider learning modules is a 5 module, online, interactive, and cost-effective educational program to support community occupational and physical therapy providers with gaining knowledge and competency with evidenced based evaluation and treatment intervention for children with Brachial Plexus Birth Injuries (BPBI). The program was developed to decrease health inequities children and families face in rural and underserved areas in accessing specialists to evaluate and treat children following BPBIs. Rural areas face critical shortages of providers who specialize in treating this condition, therefore, this author developed this program to mitigate the gap in poor access to specialty care by increasing community provider's ability to care for children within their own community. This program was developed due to the absence of similar educational programs on this topic that not only aims to increase community provider knowledge and competence, but also to develop a community provider network to allow for formal and informal mentoring amongst providers.

Available Resources

Program Participants

The primary personnel who will be designing and carry out the programming will be the primary occupational and physical therapists on the Boston Children's Hospital (BCH) Brachial Plexus Team who also serve as the lead therapists on the Physical and Occupational Therapy Department's Brachial Plexus subcommittee. Educational

materials related to OT/PT non-surgical and post-surgical therapeutic interventions, which have already been developed by the lead occupational and physical therapists will be presented to the orthopedic surgeons on BCH's Brachial Plexus team during a one-hour team meeting each year, for collaborative planning. Participating orthopedists have agreed to volunteer their time to present on key topics during the educational modules in support of their patients and community providers. The PT/OT BP subcommittee will keep up-to-date literature and evidence related to evaluation and treatment planning, post-operative guidelines in collaboration with the Boston Children's Brachial Plexus Team as part of departmental supported allocated time for practice committees 8-10 meetings a year. During the BPBI subcommittee time, therapists will also organize conference mailings and flyers and solicit speakers from the orthopedics department and community physical and occupational therapists that have close affiliations with the Brachial Plexus Team at BCH for the once-a-year online learning modules. The program participants are committed to the mission of Boston Children's Hospital to provide high quality healthcare, lead in research and innovation, education, and enhance the health and well-being of children and families.

Budget

This section outlines the needed resources (Table 7.1) for successful implementation of the Brachial Plexus Birth Injuries: Community provider learning modules. The author's intent is to solicit funding from the hospital, the orthopedics department as well as the office of community health. This author plans to solicit funding through the hospital; however, this program will be supported by the PT/OT

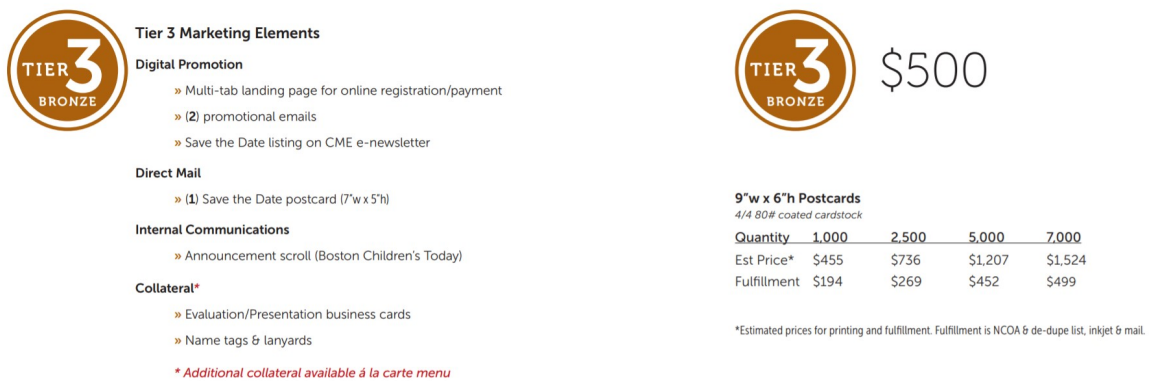
department and orthopedics department in subsequent years to continue to meet the needs and support community providers, children, and families. Ongoing funding from the program will be covered by the anticipated revenue outlined in Table 7.1. This author has plans to continue to solicit funding from the Office of Community Health at BCH and outside community health organizations in New England to decrease health disparities and inequities children with BPBI face.

Table 7.1 Boston Children’s Hospital BPBI: Community provider learning modules budget

Budget Item	OT/PT Hours per year	Cost
Planning meeting with orthopedics	2 <i>(\$45/hr.)</i>	\$90
OT/PT program preparation	21 <i>(\$45/hr.)</i>	\$945
Five 2 hr. educational modules	20 <i>(\$150/presentation hr.)</i>	\$3,000
OT/PT Facilitate discussion boards	10 <i>(\$100/facilitation hr.)</i>	\$1,000
	Total OT/PT staff time cost:	\$5,035
BCH Marketing Support		\$500
	Program costs	\$5535
Participant fee (25 participants max) <i>10 hr. class & 5 hr. discussion boards</i>	<i>Early Bird/Full Fee</i> \$255/ \$300	<i>Early Bird/Full Fee</i> \$6,375/\$7500
	Revenue	<i>Early Bird/Full Fee</i> \$840/\$1965
<i>Early bird special 15% applied if registered 3 months prior to the event date.</i>		

The budget outlined is anticipated to remain the same for each year, except for the OT/PT program preparation which this author anticipates will decrease as course content is established with the need for modifications and adaptation to content each year.

Boston Children’s Hospital Continuing Medical Education Marketing Fee Schedule
Figure 7.1



Funding

Funding for the primary occupational and physical therapist from the Brachial Plexus Program will be supported by the PT/OT Department and Department of Orthopedics for administrative time each year to (1) prepare, facilitate, and support the online learning modules during sessions and (2) allocate an additional 2–3 hours for each module to answer questions and facilitate discussion boards as needed. In-kind hours of Brachial Plexus subcommittee will be provided 4-6 times a year for 1-hour meetings as part of regularly scheduled PT/OT Department’s subcommittee best practice activities, which not only supports participants acquisition of knowledge, but BCH and the department of PT/OT’s mission to provide evidence-based interventions.

Table 7.2 Potential Funding Sources

PT/OT Department's research pilot grant	\$5,000 for first year
BCH Office of Community Health	Up to \$5,500
Dr. Gary Kielhofner Doctoral Research Scholarship in OT	\$5,000

Referral Sources

This author plans to solicit support from and market the program to directors of early intervention programs, primary care physicians, state OT Associations to reach providers at a local level. In addition, this author plans to advertise the program on AOTA Community forums and in the OT Practice Magazine because AOTA is invested in decreasing health inequities, supporting educational and professional development of their members. AOTA's marketing department will reach a broader range of OT professionals that this author may not reach without the platform of AOTA. For this reason, this program will also be advertised in the Pediatric Special Interest Section associated with AOTA to target pediatric occupational therapists.

Market Analysis

The developer of this program conducted a social assessment as discussed in Chapter 4 (Figures 4.1, 4.2, 4.3, 4.5) as the first step in the development of this series of online learning modules regarding Brachial Plexus Birth Injuries to closely consider community provider's feedback regarding their needs. A survey was sent to Early Intervention Program Directors and OT/PT providers in all New England states and randomly in New York, clearly outlining the rationale for the survey was to utilize their

feedback for the development of the actual program. This step of allowing community participation will ensure providers feel the course is relevant to their needs.

This program's pricing is competitively priced with other online conferences or webinar offerings (see appendix). Market research revealed 2-hour live webinars run around \$80.00, while 6-hour live webinars run around \$200.00. *The Brachial Plexus Birth Injuries: Community provider online learning modules* provides 10 hours of live webinar education in addition to approximately 5 hrs. of moderated discussion boards by the participating expert OT and PT. The rate for the course is set at \$255 (early bird) or \$300 regular price, in addition to the recordings of the live sessions being available to participants for up to 6 months following the close of the course. This author spoke to 2 early intervention providers who reported they only receive \$250.00 in continuing education reimbursement from their employers a year, however, on average states require between 20-30 contact hours of continuing education for OT recertification every 2 years. This author plans to seek CEU approval through AOTA to offer CEU credits to participants, which would make this course very appealing to EI providers and EI directors.

Table 7.3 AOTA CEU approved provider costs

Application for Recognition as a Provider	
Tier 1: ≤9 activities annually	\$575
Tier 2: 10–49 activities annually	\$1,125
Tier 3: ≥50 activities annually	\$1,375
Application for Professional Development Activity Approval	\$75 per activity
Annual Report Review	
Tier 1: ≤9 activities annually	\$300
Tier 2: 10–49 activities annually	\$500
Tier 3: ≥50 activities annually	\$1,250
Change in Scope Request	\$225

Conclusion

To ensure the development and implementation of the BPBI: Community provider education modules is cost effective and informative, and meets the needs of community OTs and PTs, this author conducted a social assessment as outlined in Chapter 4 to ensure programming is in line with community providers' needs. This author also took into consideration clinical, personal, and environmental factors specialty providers at BCH have identified as common barriers to good outcomes for children with BPBIs. This author's close consideration of successful educational collaborations and formats between specialist and community providers found in the available literature, guided the outlined budget to allow the BCH brachial plexus team of specialist and the PT/OT department's BP subcommittee to provide community providers the opportunity to gain the knowledge and competence with treatment of brachial plexus birth injuries on an annual basis. The program will conduct program evaluations each year to ensure it meets community OT and PT adult learners needs and that it meets the goal of building a community provider network to allow greater ability to exchange information and

develop mentorship opportunities outside of the program. The program evaluation will also guide the program in seeking grant funding as needed if enrollment changes and revenues do not fully cover the cost of personnel's time, analysis of data or marketing costs.

CHAPTER EIGHT – Conclusion

This author developed the *Brachial Plexus Birth Injuries: Community provider educational modules* following extensive review of the evidence in the literature on the key ingredients of successful telehealth and tele-conferencing collaborative programs between specialty providers and community providers (Ashburner et al., 2016; Bywood et al., 2013; Careau et al., 2008; Day et al., 2012; González-Espada et al., 2009; Mahnke et al., 2011; Shivji et al., 2011; Ray et al., 2015). The positive benefits consistently identified in the literature referenced above include:

- improved ability to properly diagnosis patients and determine level of acuity
- improved community provider knowledge and competence with management of complex or rare conditions for patients
- significant reduction of healthcare dollars spent by decreasing the need to transfer patients' long distances
- reduced financial burden on patients and families to travel distances for consultation from specialty providers
- increased community provider's knowledge and competence for caring for children in their own communities.

This author's doctoral project applied Community Engagement Theories as evidenced in the utilization of qualitative and quantitative data obtained from *the Community Provider Feedback Survey re: BPBI* that this author developed and sent to community providers in New England and New York. Consistent with evidence in the literature, occupational and physical therapists that responded to the *Community Provider*

Feedback Survey re: BPBI, indicated they live quite a distance from specialists that evaluate and treat children with BPBI which places them at risk for provider isolation. Therefore, this author determined it was very important to use this program as an avenue to build a network of community providers to care for children with BPBIs.

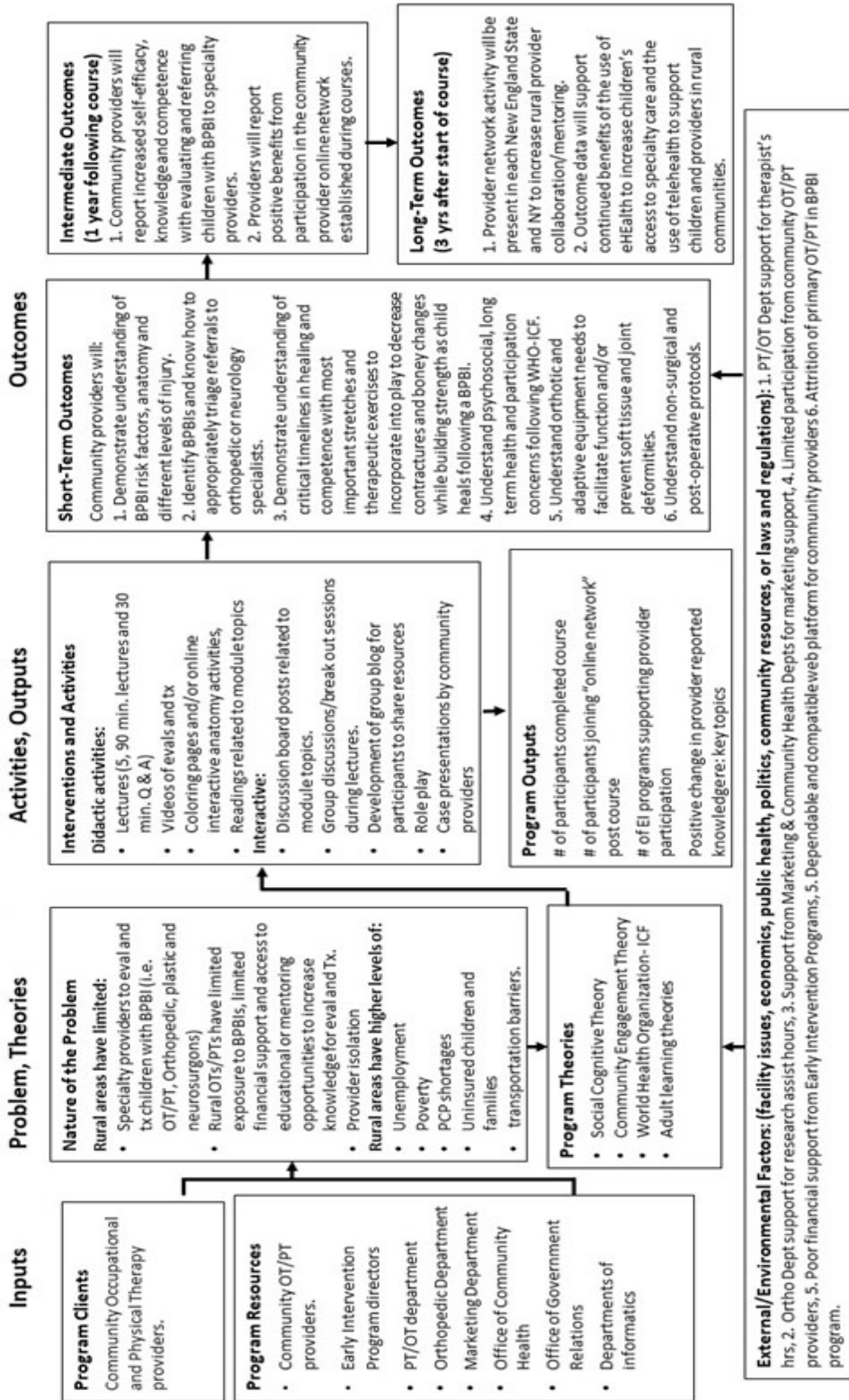
The didactic and interactive learning activities of the program were designed based on adult learning theories (Bandura, 1999) which show adult learners are more engaged when they feel they have some control over their learning. A second component of adult learning theories that were applied to the program is the clear evidence that active learning activities have been shown to be much more effective in integrating knowledge into individual's practice (Graham et al., 2009; Graham et al., 2013; Little et al., 2018; Mahoney et al., 2004; Siller & Sigman, 2002; Vismara et al., 2013; Wallisch et al., 2019). Therefore, this author purposefully designed the Community provider feedback survey re: BPBI to collect important data from community providers on their knowledge, experience, and comfort level with treating children with BPBIs as well as the key topics they would like to see included in the *BPBI: Community provider education modules* to ensure participants would be engaged and able to transfer knowledge directly to their practice.

In closing, it is this author's goal to reassess the program outcomes directly after each course, at one year, and three years after the course to ensure the program is meeting the desired outcomes and goals of the program by increasing community provider's knowledge and competence, and self-efficacy so that they can be agents in decreasing health inequities in their own communities. Lastly, it is this author's hope that this

program may serve as a model for online educational collaboratives between specialists and community providers to improve the care of children with rare, or complex medical conditions living in rural areas.

Appendix A – Logic Model

Program title: *Community provider online educational modules re: Brachial Plexus Birth Injuries*
 Margaret Maynard, M. Ed., OTR/L, BCP, CHT, FNAP



Appendix B – Brachial Plexus Birth Injuries Learning Modules

<p>Brachial Plexus Birth Injuries Community Provider Learning Modules Program Manual <i>Margaret C. Maynard M. Ed., OT, BCP, CHT, FNAP</i></p>
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Module 1	Etiology and epidemiology of BPBI Content and Activities
	<p>Welcome and introductions Present:</p> <ul style="list-style-type: none"> • Anatomy • Etiology/Epidemiology • Differential dx. • Clinical Patterns of Injury • Extent of Injury • Historical management/History of BCH Program <p>Didactic Activities: Coloring sheets of</p> <ol style="list-style-type: none"> 1. Brachial plexus 2. Muscles: origins, insertions, and nerve innervation 3. Interactive Anatomy online <p>Class Blackboard</p> <ol style="list-style-type: none"> 1. Post a link to a website that you found easy to navigate with good reference for Anatomy of BP and Upper limb. 2. Also find one interesting article related to epidemiology and discuss how this article resonated with you based on what you know or something that resonated with you and the clients you work with.
Module 2	Evaluation of BPBI Content and Activities
	<ol style="list-style-type: none"> 1. WHO-ICF model 2. Tools commonly used <ul style="list-style-type: none"> • Age ranges • Active Movement Scale, Mallet, Toronto 3. Manual and clinical observation <ul style="list-style-type: none"> • AROM, PROM • Patterns of BPBI • WHO-ICF for each age range

	<p>4. Imaging</p> <ul style="list-style-type: none"> ● X-Ray ● Ultrasound ● MRI <p>5. Overview of current medical approaches and surgical milestones medical/technical advancements</p> <ul style="list-style-type: none"> ● Important specialty providers to include on team. ● GH joint considerations ● Nerve grafting versus nerve transfers ● Tendon Transfer ● Osteotomy <p>6. Critical Timelines related to surgical decision making.</p> <ul style="list-style-type: none"> ● Infants ● Toddler to Preschool ● School-age ● Adolescent <p>Activity:</p> <ul style="list-style-type: none"> ● Thinking about the need to assess AROM in gravity eliminated planes as well as anti-gravity planes followed by PROM assessments, work with your next patient/client and intentionally assess AROM/PROM and reflect on how you might measure these with a child with BPBI for each age range. ● Infants ● Toddler to Preschool ● School-age ● Adolescent
Module 3	<p>Treatment interventions of BPBI at different ages Infant, Toddler, School-Aged, Adolescent & Young Adult Content and Activities</p>
	<p>1. Patient, Family/Caregiver Education</p> <ul style="list-style-type: none"> ● Role of OT and PT in clinic and home ● Health Literacy ● Parent PTSD <p>2. Clinical Evaluation and Treatment Recommendations (soft tissue length, strength, function, participation, orthotic use, and serial casting)</p> <ul style="list-style-type: none"> ● Infants ● Toddler to Preschool ● School-age ● Adolescent

	<p>Activity:</p> <ul style="list-style-type: none"> ● Please think of 3 activities you would do in each age range in both the gravity eliminated and anti-gravity planes for each muscle group and share/post your ideas with your peers. This is intended to spur your thinking, share your creativity, and build a library of fun activities for all participants. <p>Peer Feedback:</p> <ul style="list-style-type: none"> ● Please comment on 2 activities for 2 or your peers. These can be questions to create dialogue or to expand activity ideas so that the same activity could be used in a different way to achieve a different goal you might have. Define what that different goal might be.
Module 3	Alternative/supplemental Therapeutic Interventions Content and Activities
	<p>Adjunct therapy</p> <ul style="list-style-type: none"> ● Botox ● Orthotics/splinting ● Kinesio Tape ● Electric stimulation (E-Stim) <p>Activity:</p> <ul style="list-style-type: none"> ● Discuss an instance when you might have used an adjunct therapy or modality to support a child you worked with. Discuss the pros and cons and ask your peers a question. ● Respond to one peer's post to either answer a question, comment on your experience or continue the conversation based on your experience and possibly an outcome you observed from using an adjunct therapy or modality.
Module 4	Microsurgery, Soft Tissue and Boney Surgeries Content and Activities
	<p>Surgical interventions</p> <ul style="list-style-type: none"> ● Nerve grafting versus nerve transfers ● Tendon Transfer ● Osteotomy <p>Post-Operative Guidelines</p> <ul style="list-style-type: none"> ● Nerve grafting versus nerve transfers ● Tendon Transfer ● Osteotomy <p>Activity:</p> <ul style="list-style-type: none"> ● Discuss post-operative protocol and role play how you would discuss the surgery and precautions with a family. Explain how they would complete ADLs and care for their child following precautions.

Module 5	Psychosocial and participation in occupations Content and Activities
	<p>Personal and Social factors</p> <ul style="list-style-type: none"> ● Pain ● Obesity ● Psychosocial ● Vocational and Transition <p>Activity:</p> <ul style="list-style-type: none"> ● Discuss factors that may cause pain and potential variables that OT may be able to modify for child and family. ● Discuss factors that may cause obesity and identify one modifiable variable you may be able to play a role in to change risk of obesity and/or decrease weight. ● Discuss a psychosocial concern you have observed or experienced with either a child or a family member related to the child’s BPBI. What was the concern and how did you handle it? Was it successful or do you have ideas of how you might handle it the next time based on what you know now? ● Provide feedback to a peer on the above situation/observation a peer discussed. Do you have additional resources or thoughts that could be helpful to your peer or family they are working with?

Construct that supports...	Social Cognitive Theory
Capacity	<ul style="list-style-type: none"> ● Increase community provider’s knowledge about BPBI via multi-modal approach when presenting educational content to allow for active learning.
Observational learning	<ul style="list-style-type: none"> ● Presentation of videos or live observation of “expert” completing evaluation of child (preferably in different age ranges) to show appropriate positioning of child to complete evaluation using different toys and activities. ● Show video of parent/caregiver interview to model evaluation of patient and family occupational profile including psychosocial strengths and barriers.
Reinforcements	<ul style="list-style-type: none"> ● Collaboration and presentation of ideas formulated individually or in small groups. Participation in Blackboard discussions and the blog associated with the program. ● Participation in presentations for the program in subsequent years.
Self-control	<ul style="list-style-type: none"> ● Have community providers complete a pre and post self-assessment of knowledge and confidence.

Self-efficacy	<ul style="list-style-type: none">● Provide community providers references and didactic activities to be completed independently or even trialed with children on their caseload between e-learning modules, then have them complete written self-reflection to share with the other community providers participating in the program.
Environment	<ul style="list-style-type: none">● Community of learners and providers, taking part in “safe space” programming.

Appendix C – Community Provider Feedback Survey

Community Provider Feedback Survey re: Brachial Plexus Birth Injuries

1. How many years have you been an occupational or physical therapist?	
2. Have you evaluated or treated a child with a diagnosis of a Brachial Plexus Birth Injury in your career?	
3. How many children with this diagnosis have you worked with total?	
4. On average, how old was the child when they first started working with you?	1-3 months ____ 4-6 months ____ 7-12 months ____ 1 -2 years ____
5. How close is your community to a pediatric orthopedist or plastic surgery providers that can assess and treat children with BPBIs?	1 – 10 miles ____ 10 – 25 miles ____ 25 – 50 miles ____ 50+ miles
Community Provider Survey Likert Scale	
(pre-course and post-course)	
1= Unfamiliar/uncomfortable/no experience with diagnosis	
2= Somewhat familiar/somewhat comfortable/ have heard about diagnosis	
3= Comfortable/novice or with basic knowledge, non-surgical interventions/relies on mentoring for treatment planning.	
4= Good understanding of diagnosis/Comfortable with evaluating and treating/seek guidance from advanced skilled practitioners following surgical interventions.	

Knowledge about the risks associated with Brachial Plexus Birth Injuries.	1 2 3 4 5
Knowledge about the causes of Brachial Plexus Birth Injuries.	1 2 3 4 5
Assessment and identification of typical patterns BPBI.	1 2 3 4 5
Knowledge of important exercises.	1 2 3 4 5
Knowledge of important timelines in the healing process and when to refer a child and family to a specialist.	1 2 3 4 5

Knowledge of common surgical interventions.	1	2	3	4	5
Knowledge of micro nerve surgeries	1	2	3	4	5
Knowledge of soft tissue surgeries	1	2	3	4	5
Knowledge of boney surgeries	1	2	3	4	5
Knowledge of common psychological barriers for parents following BPBI.	1	2	3	4	5
Knowledge about child’s participation in activities in school, community, and home environments.	1	2	3	4	5
Knowledge about common orthosis or splints used with the BPBI population to prevent contractures, joint deformities and/or increase participation/function.	1	2	3	4	5

What would you like to know more about? (Check all that apply)

- Anatomy of BP and impact of injury on function _____
- Important timelines in the healing process _____
- Evaluation and treatment interventions at different age ranges _____
- Orthotic use (prefabricated and/or customized) _____
- Psychological health and common impact of personal and environmental factors

- Obesity in the BPBI population _____
- Adaptive Driving and Vocational planning _____
- Secondary and higher education planning, including transition to independent living. _____
- Other _____

Appendix D – Post-Course, 1 year and 3-year follow-up survey

BPBI: Community Provider Online Learning Modules Post-Course, 1 year and 3-year follow-up survey

Formative
1. Did you find the live presentations online more, or less beneficial, than reviewing recorded presentations? <i>Open ended questions</i>
2. Which activities supported your learning best? <i>Open ended questions</i>
3. Were there positive benefits from participation in the community provider online network established during the program? <i>Open ended questions</i>
4. Was it easy to participate in the program through the online platform? <i>Open ended questions</i>
5. Is there an increased sense of community through the online network established during the course? <i>Open ended questions</i>
6. What changes to the course would you recommend? <i>Open ended questions</i>
7. Would you recommend this course to other community providers? (1= Strongly Disagree, 2= Disagree, 3= Agree, 4= Strongly Agree)
8. Was the course length adequate for meeting objectives of the course and learning? (1= Strongly Disagree, 2= Disagree, 3= Agree, 4= Strongly Agree)
9. Was the content presented too advanced? (1= Strongly Disagree, 2= Disagree, 3= Agree, 4= Strongly Agree)
10. Was the knowledge you gained easily applied to your practice? (1= Strongly Disagree, 2= Disagree, 3= Agree, 4= Strongly Agree)
11. Was the cost of the course reasonable? (1= Strongly Disagree, 2= Disagree, 3= Agree, 4= Strongly Agree)
12. Are the resources provided on the “Community provider Blog” helpful? (1= Strongly Disagree, 2= Disagree, 3= Agree, 4= Strongly Agree)
13. Are you satisfied with your investment in the program? (1= Strongly Disagree, 2= Disagree, 3= Agree, 4= Strongly Agree)

Summative
<ul style="list-style-type: none"> Did this course increase your self-efficacy and competence with evaluating, treating and referring children with BPBI to the appropriate specialty providers? (1= Strongly Disagree, 2= Disagree, 3= Agree, 4= Strongly Agree)
Community Provider Survey Likert Scale
(pre-course and post-course)
1= Unfamiliar/uncomfortable/no experience with diagnosis
2= Somewhat familiar/somewhat comfortable/ have heard about diagnosis
3= Comfortable/novice or with basic knowledge, non-surgical interventions/relies on mentoring for treatment planning.
4= Good understanding of diagnosis/Comfortable with evaluating and treating/seeks guidance from advanced skilled practitioners following surgical interventions.



Knowledge about the risks associated with Brachial Plexus Birth Injuries.	1	2	3	4	5
Knowledge about the causes of Brachial Plexus Birth Injuries.	1	2	3	4	5
Assessment and identification of typical patterns BPBI.	1	2	3	4	5
Knowledge of important exercises.	1	2	3	4	5
Knowledge of important timelines in the healing process and when to refer a child and family to a specialist.	1	2	3	4	5
Knowledge of common surgical interventions.	1	2	3	4	5
Knowledge of micro nerve surgeries	1	2	3	4	5
Knowledge of soft tissue surgeries	1	2	3	4	5
Knowledge of boney surgeries	1	2	3	4	5
Knowledge of common psychological barriers for parents following BPBI.	1	2	3	4	5
Knowledge about child's participation in activities in school, community, and home environments.	1	2	3	4	5


Knowledge about common orthosis or splints used with the BPBI population to prevent contractures, joint deformities and/or increase participation/function.	1 2 3 4 5
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Appendix E – Sample module for BPBI: Community provider educational modules

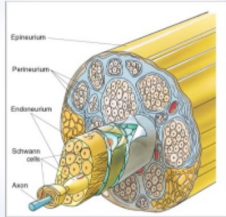
Brachial Plexus Birth Injury


Margaret Maynard M. Ed., OTR/L, BCP, CHT, FNAP
Susan Morehouse, PT, MSPT

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Nerve Anatomy

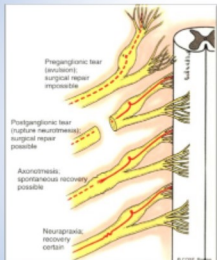


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Classifications of Nerve Injury

Seddon	Sunderland	Description
Neurapraxia	I	Complete motor paralysis
Axonotmesis	II	Loss of axonal continuity
	III	Loss of axonal continuity and endoneurium
Neurotmesis	IV	Loss of axonal continuity, endoneurium, and perineurium
	V	Complete transection of an entire nerve

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Avulsion: Nerve is torn from the spinal cord. Less common, surgery cannot repair.

Rupture: Tear of nerve outside of spinal cord. Common injury, may require surgery to repair.


Stretch (neurapraxia): Most common. Injury to nerve happens outside of spinal cord. Recovers within 3 months of life.

Phragmatonic tear (neurapraxia): surgical repair impossible

Phragmatonic tear (rupture neurotmesis): surgical repair possible

Axonotmesis: spontaneous recovery possible

Neurotmesis: recovery optimal

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Brachial Plexus Birth Injury (BPBI)

"The paralysis of the upper extremity secondary to a traction or stretch injury to the brachial plexus sustained at birth"

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Incidence

- Range between 1.5-5.1 / 1000 births
 - Variance in prenatal care
 - Regional differences in average birth weight/maternal pelvic size
- Decreased incidence in US as reported in the past
 - Increasing rates of cesarean
 - Increasing rates of labor induction
 - Increasing multiple birth rates

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Risk Factors

- Macrosomia
 - > 4.5kg
- Prolonged Second Stage Labor
- Instrumented Delivery
 - i.e. Forceps, Vacuum
- Breech Delivery
- Prior deliveries with BPBI
- Shoulder Dystocia

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Risk Factors Cont'd

- Shoulder Dystocia
 - Crowning then recession of the head with failure of the delivery of the shoulders through the birth canal

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Classification

Narakas et al.

- Group I classic upper trunk lesion C5-6
- Group II extended upper trunk lesion C5-7
- Group III flail extremity
- Group IV flail extremity + Horner's syndrome

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Narakas Group I

Absence/Weakness of:

- Shoulder ABD
- Shoulder Flexion
- External rotation
- Elbow flexion
- Forearm supination

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Narakas Group II

Absence/Weakness of:

- Shoulder ABD
- External rotation
- Elbow flexion
- Forearm supination
- Wrist extension
- Finger extension

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Narakas Group III


- Flail arm, but **no** Horner's Syndrome

Narakas Group IV

- Flail Arm
- Horner's Syndrome
- Possible Phrenic Nerve Palsy



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Prognosis

- Spontaneous recovery (66%-82%)
- Dependent on extent of injury

Group	Roots affected	Approximate rate of complete spontaneous recovery (%)
I (Upper Erb's)	C5, C6	90
II (Extended Erb's)	C5, C6, C7	65
III (Global, no Horner syndrome)	C5, C6, C7, C8, T1	<50
IV (Global, Horner syndrome)	C5, C6, C7, C8, T1	0

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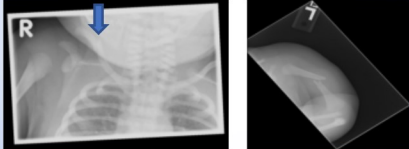
Differential Diagnosis

- Shoulder sepsis
- Osteomyelitis
- Congenital malformation of brachial plexus
- Tumors
- Neonatal stroke
- Fractures (clavicle, humerus)

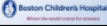
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Diagnostic Imaging/ Testing

- Fractures
 - Can occur concurrently or independent of BPBI

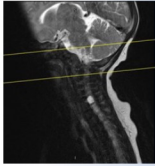


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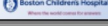


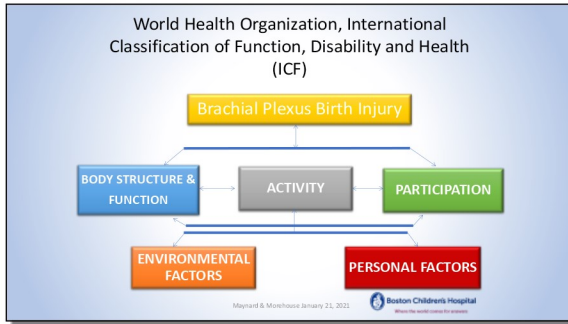
Diagnostic Imaging/ Testing

- MRI of the brachial plexus
 - Assess nerve root
 - Not utilized alone to determine nerve surgery need
- EMG/Nerve Conduction
 - Not found to be highly reliable in infants



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Critical Milestones/Timelines

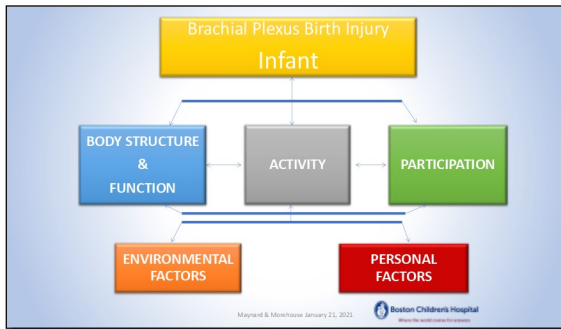
Infants

Toddler to Preschool

School-age

Adolescent

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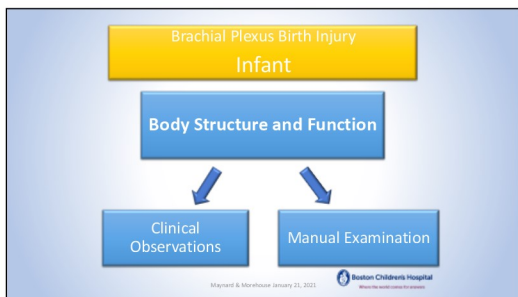


Brachial Plexus Birth Injury Infant

Body Structure and Function

- Reflexes
- Sensorimotor system
- Musculoskeletal
- Postural control
- Protective and Righting reactions

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Clinical Observations


- Spontaneous movements throughout the entire body
- Abnormal posturing and/or movement patterns

Two photographs of an infant lying on their back. Blue circles are drawn over the infant's head and neck area in both photos, highlighting areas of interest for clinical observation.

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Clinical Observations

- Upper Extremity Posture



- Cervical Positioning
 - Torticollis/Plagiocephaly

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Clinical Observations

- Integument Inspection
 - Self-mutilation




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Musculoskeletal Impairments

- Muscle weakness
- Muscle imbalance
 - Bone/joint deformity
- Joint Contracture
- Impairment of muscle length
- Impairment of bone growth

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Posterior Shoulder Dislocation

- Passive loss of external rotation in shoulder ADD \leq 60 degs. → consider ultrasound


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Ultrasound Screening for Posterior Shoulder Dislocation in Infants with Persistent Brachial Plexus Birth Palsy

Andrea S. Swan, MD, Keith E. Jones, MD, MS, Nasser Shamsi, MD, Ryan L. Anderson, MD, MS, Leslie A. Babb, ScD, and Michele A. Jones, MD

Investigative journal of Air-Boon Hospital for Children—Northern California, Sacramento, California


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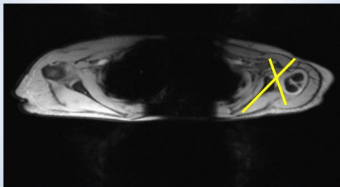
Glenohumeral Joint Deformity

Waters and Pajovic classification	
I	No deformity, retroversion of the glenoid $<$ 5° difference from the normal side and without displacement of the humeral head
II	Minimal deformity, retroversion of the glenoid $<$ 5° difference from the normal side and without displacement of the humeral head
III	Moderate deformity, retroversion of the glenoid $>$ 5° difference from the normal side and posterior subluxation $<$ 35% of the humeral head
IV	Severe deformity, false glenoid and subluxation $>$ 35% of the humeral head
V	Severe deformity, false glenoid and dislocation of the humeral head
VI	Severe deformity, false glenoid and early dislocation of the humeral head
VII	Severe deformity, false glenoid and deformity of the proximal humerus


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MRI Evaluation Glenohumeral Joint





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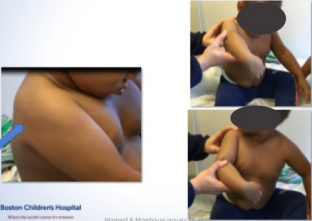
Manual Examination


Passive Range of Motion/Muscle Length




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Manual Examination





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Active Movement Scale (AMS)

Representation to all 5 nerve roots

- Shoulder Abduction
- Shoulder Adduction
- Shoulder Flexion
- Shoulder External Rotation
- Shoulder Internal Rotation
- Elbow Flexion
- Elbow Extension
- Forearm Pronation
- Forearm Supination
- Wrist Flexion
- Wrist Extension
- Finger Flexion
- Finger Extension
- Thumb Flexion
- Thumb Extension


Hospital For Sick Children Active Movement Scale	
Scale	Score
Gravity Eliminated	
No Contraction	0
Contraction, No Motion	1
<50% Range of Motion	2
>50% Range of Motion	3
Full Motion	4
Against Gravity	
<50% Range of Motion	5
>50% Range of Motion	6
Full Motion	7


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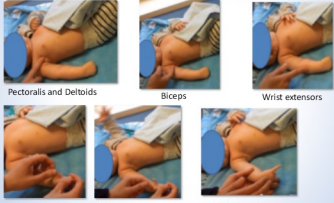
MUSCLE FUNCTION Toronto Test


- Elbow Flexion
- Wrist Extension
- Finger Extension
- Elbow Extension
- Wrist Flexion
- Thumb Extension

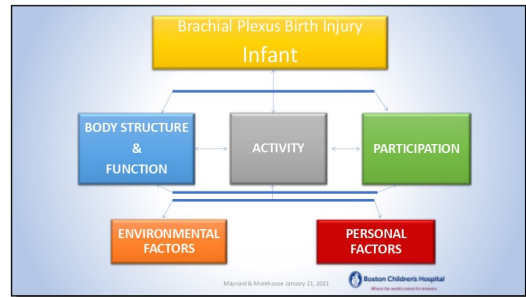
Observation	Clinical Grade	Numerical Grade
No Joint Movement	0	0
Flicker of Movement	0+	0.3
Less than 50% of range of movement	1-	0.6
50% range of movement	1	1
More than 50% range	1+	1.3
Good, but not full range	2-	1.6
Full range of movement	2	2


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MUSCLE FUNCTION




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Brachial Plexus Birth Injury
Infant

Activity

- Hands to Mouth
- Holding Bottle
- Self-soothing
- Object/Toy Manipulation
- Mobility/Transitional Movements

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Brachial Plexus Birth Injury
Infant

Participation

- Mobility/Environmental Exploration
- Social Interaction

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Brachial Plexus Birth Injury
Infant

Environmental Factors

Maternal Stress

- Health Literacy
- Daycare
- Home Setting
- Access to Services
- Insurance Coverage

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Brachial Plexus Birth Injury
Infant

Personal Factors

- Extent of Injury
- Other Comorbidities

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Infant Therapy Treatment Interventions

Optimizing Muscle Length/PROM

- Passive stretching
- Soft-tissue mobilization
- Orthotics/Splinting


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Help me keep my shoulder stretched (diaper changes)

Shoulder Abduction:
Support scapula while bringing arm to side above head
Repeat 5 times, hold 15 sec.



External rotation: Bend elbow, place arm in 90 deg. Abduction
Support scapula rotating arm to mat. Repeat 5 times, hold 15 sec.



Shoulder flexion:
Hold arm at elbow and move arm above head
Supporting scapula
Repeat 5 times, hold 15 sec.



External rotation:
Bend elbow and place arm next to trunk, supporting scapula.
Repeat 5 times, hold 15 sec.



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Help me keep my elbow, wrist and hand stretched



Elbow extension:
Hold arm straight
Repeat 5 times, hold 15 secs

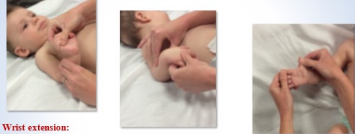
Supination:
Bend elbow and turn forearm so palm is up
Repeat 5 times, hold 15 secs

Pronation:
Bend elbow and turn forearm/palm down
Repeat 5 times, hold 15 secs

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Help me keep my elbow, wrist and hand stretched




Wrist extension:
Bend wrist up
Repeat 5 times, hold 15 secs

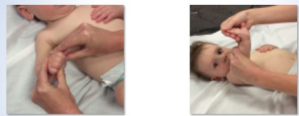
Wrist Flexion:
Bend wrist down
Repeat 5 times, hold 15 secs

Finger Extension:
Open all fingers
Repeat 5 times, hold 15 secs

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Help me keep my elbow, wrist and hand stretched



Finger Flexion: Bend all fingers into fist
Repeat 5 times, hold 15 secs

Composite wrist extension:
Hold elbow straight, open fingers and bend wrist up
Repeat 5 times, hold 15 secs

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APPENDIX F – Executive Summary

Executive Summary

The Brachial Plexus Birth Injuries: Community provider learning modules is a 5 module, innovative online, interactive, and cost-effective educational program to support community Occupational therapy (OT) and Physical therapy (PT) providers with gaining knowledge and competency with evidenced based evaluation and treatment intervention for children with Brachial Plexus Birth Injuries (BPBI). The program was developed to decrease health inequities children and families face in rural and underserved areas in accessing specialists to evaluate and treat children following BPBIs. Rural areas face critical shortages of providers who specialize in treating this condition, therefore, this author developed this program to mitigate the gap in poor access to specialty care by increasing community provider's ability to care for children within their own community.

Facts on BPBIs (Chauhan, S. et al., 2014; Frade et al., 2019):

Incidence

- Brachial Plexus Birth injuries occur in 1/ 1,000 births
- The likelihood of BPBI being permanent is 10–18%

Risk factors for BPBI include:

- Maternal obesity and other comorbidities such as diabetes.
- Poor maternal health increases the risk that infants will be of higher birth weight (macrosomia), placing mothers and infants at greater risk for complications during the delivery process.

Women living in poverty and rural areas of our country are more likely to have poor access to prenatal care, due to financial or transportation barriers which limits their ability to travel the long distances for specialty care.

This author was able to identify there are resource shortages in rural communities through quantitative and qualitative data gathered from this author’s Community provider feedback survey re: Brachial Plexus Birth Injuries. Respondents reported there were few, if any, pediatric orthopedists, plastic surgeons, or neurologists specializing in evaluation and treatment of children with BPBIs within 25-50 miles (Figure 1.1). Survey results also indicated pediatric occupational and physical therapists in rural communities report they do not have the appropriate knowledge base, or comfort level to treat children with BPBI, requesting educational topics that are key to appropriate evaluation and treatment of children with BPBI (Table 1.1).

Figure 1.1 Distance to closest pediatric orthopedist or plastic surgeon

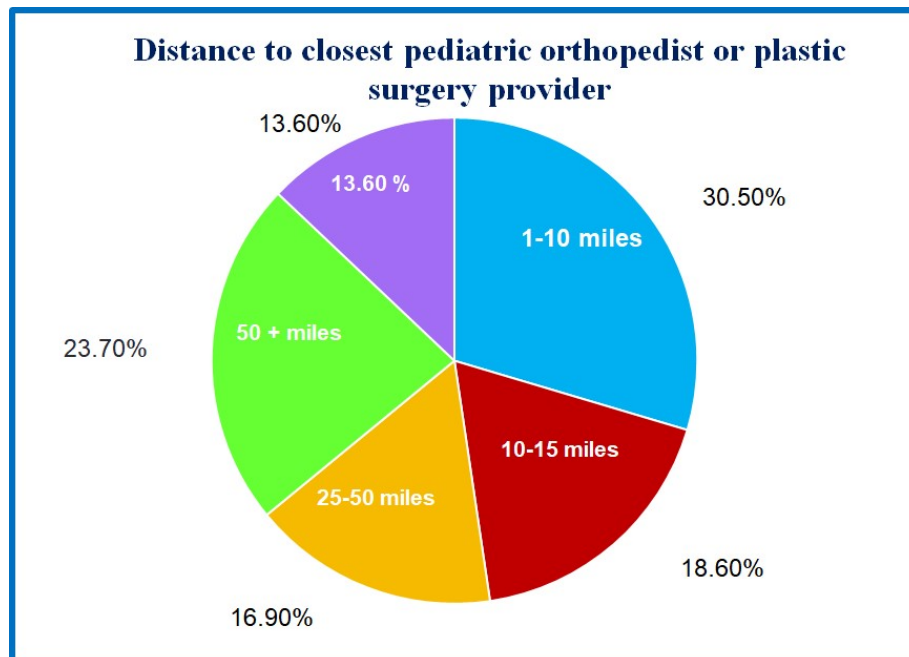


Table 1.1 Community provider requested educational topics

	Educational topics requested by community providers
43%	Anatomy of the brachial plexus and impact on injury
80%	Important timelines in the healing process
85%	Evaluation and treatment of BPBI
66.7%	Orthosis use to avoid soft tissue, boney deformities and <u>facilitate</u> function
50%	Psychological health and impact of personal and environmental factors
20%	Obesity in the BPBI population.

These factors outlined above perpetuate health inequities and the potential for increased disability and decreased satisfaction with life for children with BPBI. Given the legislative, health insurance and professional board regulation barriers, which prohibit the use of Telehealth to access specialty care across state lines, it is ethically and morally essential that we provide affordable, and accessible, online education modules to increase community provider’s knowledge, competence, and self-efficacy to work with children and their families within their own communities.

Program Description

Program Vision

Build a supportive network of community providers, which will create a platform for ongoing knowledge translation and provider competency. By building stronger collaborations between specialty and community providers, we can increase the potential that the necessary expertise for the evaluation and treatment of children with BPBI will be more readily available to address the health inequities children and their families face in rural and underserved areas.

Program Mission

Increase community provider knowledge and competency for treating children with BPBI through a collaborative educational platform between specialty providers and community OTs and PTs in a series of live, online learning modules. Goals at the heart of the program to be met by community providers to better serve children with BPBIs and decrease health inequities include:

1. Decrease the risk of soft tissue and bony deformities,
2. Reduce the risk of limited participation and socialization,
3. Decrease the risk of depression and obesity,
4. Decrease the risk for barriers in vocational opportunities for children with a BPBI.

The *Brachial Plexus Birth Injuries: Community provider learning modules* is an online, interactive, and cost-effective educational platform to support community Occupational and Physical therapy providers with gaining knowledge and competency with evidenced based evaluation and treatment intervention for children with BPBI. This program includes lectures by Boston Children's Hospital's (BCH) orthopedic hand surgeons, and primary occupational and physical therapists from the Brachial Plexus Program at BCH. The program also incorporates learning activities inclusive of reviewing current evidence in the research literature related to surgical and non-surgical treatment interventions, critical time frames in the recovery and healing phases following the birth injury and surgical interventions and the role of OT and PT. Additional learning opportunities involve online discussion boards and collaborative learning activities to cultivate the development of a community provider network, to better support families

with a child who has sustained a BPBI.

Conclusion

This author has developed a unique series of online educational modules on BPBI, considering the many social, economic and health disparities children and families in rural, underserved communities or in marginalized populations experience. The program is based on the positive outcomes reported in the literature regarding how telehealth, tele-educational and teleconsultations between subspecialists and community providers can increase knowledge and competence of the community provider and ability to care for children with complex medical conditions within their community (Ashburner et al., 2016; Bywood et al., 2013; Careau et al., 2008; Day et al., 2012; González-Espada et al., 2009; Mahnke et al., 2011; Shivji et al., 2011; Ray et al., 2015) . Given this program was developed with adult learners' needs in mind for successful engagement in learning activities, the secondary outcome we hope to achieve is that the program will be able to build a supportive network of community providers to support ongoing knowledge translation and competency. By building stronger collaborations between specialty and community providers we can make the necessary expertise readily available to address the health inequities these children and their families face.

References:

- Ashburner, J., Vickerstaff, S., Beetge, J. & Copley, J. (2016) Remote versus face-to-face delivery of early intervention programs for children with autism spectrum disorders: Perceptions of rural families and service providers. *Research in Autism Spectrum Disorders*, 23, 1-14. <http://ees.elsevier.com/RASD/default.asp>
- Bandura, A. (1999). Social cognitive theory: An agentic perspective. *Asian Journal of Social Psychology*, 2, 21-41. <https://doi.org/10.1111/1467-839X.00024>
- Bywood, P., Raven, M., & Butler, C. (2013). Telehealth in primary health care settings within Australia and internationally. *PHC RIS policy issue review*. Adelaide: Primary Health Care Research & Information Service.
- Careau, E., Vincet, C., & Noreau, L. (2008). Assessing interprofessional teamwork in a videoconference-based telerehabilitation setting. *Journal of Telemedicine and Telecare*, 14, 427–434. <http://dx.doi.org/10.1258/jtt.2008.080415>.
- Chauhan, S., Blackwell, S. & Ananth, C. (2014). Neonatal brachial plexus palsy: Incidence, prevalence and temporal trends. *Seminars in Perinatology*, 38, 210-218.
- Day, K., & Kerr, P. (2012). Telemedicine: rethinking healthcare roles for smarter care. *Health Care and Informatics Review Online*, 16 (2), 8–16.
- Frade, F., Gomez-Salgado, J., Jacobsohn, L. & Florindo-Silva, F. (2019). Rehabilitation of neonatal Brachial Plexus Palsy: Integrative literature review. *Journal of Clinical Medicine*, 8, 980, 1-12. doi:10.3390/jcm8070980
www.mdpi.com/journal/jcm

González-Espada, W., Hall-Barrow, J., Whit Hall, R., Burke, B. & Smith, C. (2009).

Achieving success connecting academic and practicing clinicians through telemedicine. *Pediatrics*, (123), 3, e476- 483

<http://pediatrics.aappublications.org/content/123/3/e476>

Mahnke, C., Jordon, C., Bergval, E. Person, D. & Pinsker, J. (2011). The Pacific

Asynchronous TeleHealth (PATH) System: Review of 1,000 pediatric teleconsultations. *Telemedicine and e-Health*, 17, 1, 1-5. DOI:

10.1089/tmj.2010.0089

Ray, K., Demirci, J., Bogen, D., Mehrotra, A. & Miller, E. (2015). Optimizing telehealth strategies for subspecialty care: Recommendations from rural pediatricians.

Telemedicine and e-Health, 21,8, 622-629. DOI: 10.1089/tmj.2014.0186

Shivji, S., Metcalfe, P., Khan, A. & Bratu, I. (2011). Pediatric surgery telehealth: patient and clinician satisfaction. *Pediatric Surgery International*, 27, 523–526. DOI

10.1007/s00383-010-2823-y

APPENDIX G – Fact Sheet



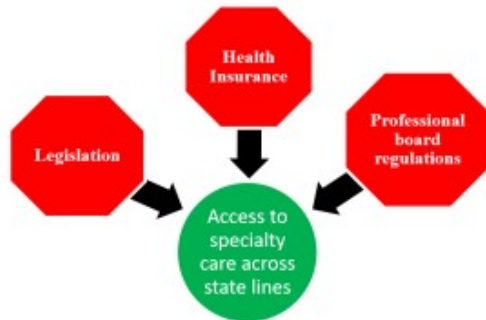
**Brachial Plexus Birth Injuries:
Online Community Provider Learning Modules**

Margaret C. Maynard M. Ed., OT, BCP, CHT, FNAP

Problem

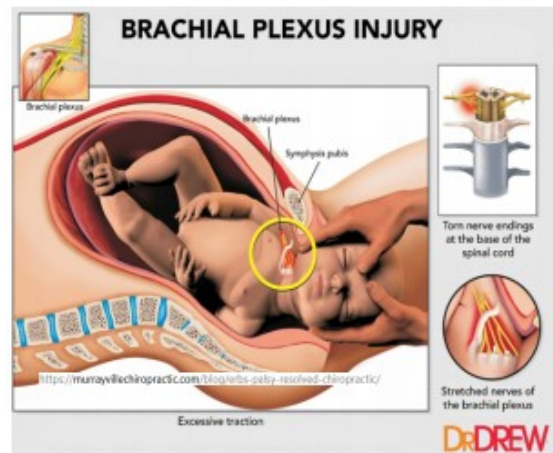
Brachial Plexus Birth injuries (BPBI) occur 1/1000 births and is a result of a excessive traction on child's neck when the child's shoulder gets caught on the mother's pubic bone during the delivery process (fig. 1). The nerves that come from the spinal cord and power the muscles in the arm are damaged, with the potential of 10%-18% of injuries being permanent (Chauhan, S. et al., 2014; Frade et al., 2019). Rural areas face critical shortages of healthcare providers who specialize in treating children who have sustained a BPBI, and the restrictions in place by state legislation, professional licensing boards, and health insurance companies (Fig. 2), add to the barriers in accessing specialty care across state lines, which can lead to poor outcomes.

Fig. 2 Barriers to accessing specialty care



Photograph: iStock/Getty

Fig. 1 Brachial Plexus Birth Injury



Aim of program

- Mitigate healthcare inequities children with BPBI in rural areas face in accessing specialty care, by increasing community OT and PT provider's knowledge, competence with evaluation and treatment interventions, while increasing provider self- efficacy to better care for children in their community.
- The program's secondary aim is to build a strong community provider network for formal and informal mentoring.

Increased community provider knowledge and competence with evaluation and treatment interventions, decreases children with BPBI's risk of:

1. Soft tissue and bony deformities.
2. Limited participation and socialization.
3. Depression and obesity.
4. Barriers in vocational opportunities for children with a BPBI.

Community provider feedback survey re: Brachial Plexus Birth Injuries (n=61)

Fig. 1 Distance to closest specialists

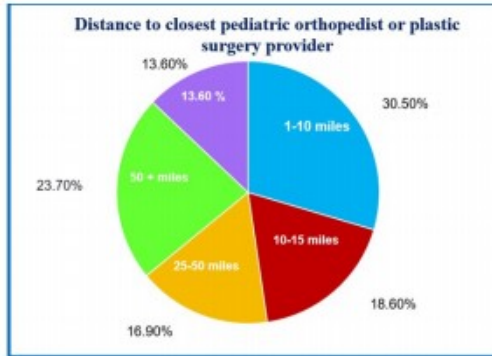


Table 1 Community provider requested educational topics

	Educational topics requested by community providers
43%	Anatomy of the brachial plexus and impact on injury
80%	Important timelines in the healing process
85%	Evaluation and treatment of BPBI
66.7%	Orthosis use to avoid soft tissue, bony deformities and facilitate function
50%	Psychological health and impact of personal and environmental factors
20%	Obesity in the BPBI population.

Description of Program

Target population: Community Occupational therapy (OT) and Physical therapy (PT) providers

Program Goal: Increase OT/PT providers' knowledge and competency with evidenced based evaluation and treatment intervention for children with Brachial Plexus Birth Injuries (BPBI).

Program's Guiding Theories: Social Cognitive Theory, Community Engagement Theory, World Health Organization-ICF, and Adult learning theories

Program Format: Interactive live online educational modules, recorded for participant viewing up to 1 year.

Program Interventions and Activities

Didactic activities: Five, live 90 min. lectures and 30 min. Q & A, videos of evaluations and treatments, interactive anatomy activities, research readings

Interactive: Discussion board posts, group discussions/breakout sessions, group blog, case presentations



Picture courtesy of Julia Solomon

References:

- Bandura, A. (1999). Social cognitive theory: An agentic perspective. *Asian Journal of Social Psychology*, 2, 21-41. <https://doi.org/10.1111/1467-839X.00024>
- Chauhan, S., Blackwell, S. & Ananth, C. (2014). Neonatal brachial plexus palsy: Incidence, prevalence and temporal trends. *Seminars in Perinatology*, 38, 210-218.
- Day, K., & Kerr, P. (2012). Telemedicine: rethinking healthcare roles for smarter care. *Health Care and Informatics Review Online*, 16 (2), 8-16.
- Frade, F., Gomez-Salgado, J., Jacobssohn, L. & Florindo-Silva, F. (2019). Rehabilitation of neonatal Brachial Plexus Palsy: Integrative literature review. *Journal of Clinical Medicine*, 8, 980, 1-12. doi:10.3390/jcm8070980 www.mdpi.com/journal/jcm
- Gonzalez-Espada, W., Hall-Barrow, J., Whit Hall, R., Burke, B. & Smith, C. (2009). Achieving success connecting academic and practicing clinicians through telemedicine. *Pediatrics*, (123), 3, e476-483 <http://pediatrics.aappublications.org/content/123/3/e476>
- Ray, K., Demirci, J., Bogen, D., Mehrotra, A. & Miller, E. (2015). Optimizing telehealth strategies for subspecialty care: Recommendations from rural pediatricians. *Telemedicine and e-Health*, 21, 8, 622-629. DOI: 10.1089/tmj.2014.0186
- Shivji, S., Metcalfe, P., Khan, A. & Bratu, I. (2011). Pediatric surgery telehealth: patient and clinician satisfaction. *Pediatric Surgery International*, 27, 523-526. DOI 10.1007/s00383-010-2823-y

REFERENCES

- Adler-Milstein, J., Kvedar, J. & Bates, D. (2017). Telehealth among US hospitals: Several factors, including state reimbursement and licensure policies, influence adoption. *Health Affairs*, 33(2), 207-215. doi:10.1377/hlthaff.2013.1054.
Retrieved from <http://content.healthaffairs.org/content/33/2/207.full>
- Akhbari Ziegler, S., Dirks, T., & Hadders-Algra, M. (2019). Coaching in early physical therapy intervention: The COPCA program as an example of translation of theory into practice. *Disability and Rehabilitation*, 41, 1846–1854.
<https://doi.org/10.1080/09638288.2018.1448468>
- American Medical Association. (2017). Issue brief: Interstate medical licensure compact.
Retrieved from <https://www.ama-assn.org/>
- Ashburner, J., Vickerstaff, S., Beetge, J. & Copley, J. (2016) Remote versus face-to-face delivery of early intervention programs for children with autism spectrum disorders: Perceptions of rural families and service providers. *Research in Autism Spectrum Disorders*, 23, 1-14. <http://ees.elsevier.com/RASD/default.asp>
- Arora, S., Thornton, K., Murata, G., Deming, P., Kalishman, S., Dion, D., Parish, B., Burke, T., Pak, W., Dunkelberg, J. & Kistin, M. (2011). Outcomes of treatment for hepatitis C virus infection by primary care providers. *New England Journal of Medicine* 364(23), 2199–2207.
- Baharav, E., & Reiser, C. (2010). Using telepractice in parent training in early autism. *Telemedicine and e-Health*, 16, 727–731.

- Bandura, A. (1999). Social cognitive theory: An agentic perspective. *Asian Journal of Social Psychology*, 2, 21-41. <https://doi.org/10.1111/1467-839X.00024>
- Bywood, P., Raven, M., & Butler, C. (2013). Telehealth in primary health care settings within Australia and internationally. *PHC RIS policy issue review*. Adelaide: Primary Health Care Research & Information Service.
- Callas, P., Ricci, M., Caputo, M. (2000). Improved rural provider access to continuing medical education through interactive videoconferencing. *Telemedicine Journal and eHealth* 6,(4), 393–399.
- Careau, E., Vincet, C., & Noreau, L. (2008). Assessing interprofessional teamwork in a videoconference-based telerehabilitation setting. *Journal of Telemedicine and Telecare*, 14, 427–434. <http://dx.doi.org/10.1258/jtt.2008.080415>.
- Center for Connected Health Policy (2015, February). *State telehealth laws and reimbursement policies: a comprehensive scan of the 50 states and the District of Columbia*. Retrieved March 2, 2015, from <http://cchpca.org/sites/default/files/resources/State%20Laws%20and%20Reimbursement%20Policies%20Report%20Feb%20%202015.pdf>.
- Center for Connected Health Policy: The National Telehealth Policy Resource Center. (2017). Telehealth policy. Retrieved from <http://www.cchpca.org/telehealth-policy>
- Chauhan, S., Blackwell, S. & Ananth, C. (2014). Neonatal brachial plexus palsy: Incidence, prevalence, and temporal trends. *Seminars in Perinatology*, 38, 210-218.

- Committee on pediatric workforce (2015) The use of telemedicine to address access and physician workforce shortages. *American Academy of Pediatrics*, (136), 1, 202-211.
- Covert, L. T., Slevin, J. T., & Hatterman, J. (2018). The effect of telerehabilitation on missed appointment rates. *International Journal of Telerehabilitation*, 10(2), 65–72. doi:10.5195/IJT.2018.6258
- Day, K., & Kerr, P. (2012). Telemedicine: rethinking healthcare roles for smarter care. *Health Care and Informatics Review Online*, 16 (2), 8–16.
- Duan, C., Kane, J. & Watney, C. (2018, April). *Telemedicine: Lessons for – and from-emerging technology policy*. R Street Policy Study No. 139, 1-7.
<https://www.rstreet.org/wp-content/uploads/2018/04/Final-139-for-posting.pdf>
- Dunn, W., Cox, J., Foster, L., Mische-Lawson, L., & Tanquary, J. (2012). Impact of a contextual intervention on child participation and parent competence among children with autism spectrum disorders: a pretest–posttest repeated-measures design. *American Journal of Occupational Therapy*, 66, 520–528.
<http://dx.doi.org/10.5014/ajot.2012.004119>.
- Dutton, R. (1998). Biomechanical frame of reference. In: Neistadt, M. E., Crepeau, E.B. (Eds.), *Willard and Spackman's Occupational Therapy*. (9th ed.) Lippincott.
- Fathi, J., Modin, H. & Scott, J. (2017). Nurses advancing telehealth services in the era of healthcare reform. *The online Journal of Issues in Nursing*, 22 (2), Manuscript 2.
DOI: 10.3912/OJIN.Vol22No02Man02

Federal Communications Commission (FCC). Connect2HEalthFCC Data.

[Sss.fcc.gov/reports-research/maps/connect2health/data.html](https://www.fcc.gov/reports-research/maps/connect2health/data.html)

Federal Communications Commission (FCC). Mapping broadband health in America.

<https://www.fcc.gov/health/maps>

Feil, Baggett, Davis, Sheeber, Landry, Carta, et al. (2008). Expanding the reach of preventive interventions: Development of an internet-based training for parents of infants. *Child Maltreatment, 13*, 334–346.

Fixen, D., Blase, K., Naoom, S. & Wallace, F. (2009). Core implementation components. *Research on Social Work Practice, 19*, 531-540.

Foster, L., Dunn, W., & Mische-Lawson, L. (2013). Coaching mothers of children with autism: a qualitative study for occupational therapy practice. *Physical & Occupational Therapy in Pediatrics, 33*, 253–263.
<http://dx.doi.org/10.3109/01942638.2012.747581>.

Frade, F., Gomez-Salgado, J., Jacobsohn, L. & Florindo-Silva, F. (2019). Rehabilitation of neonatal Brachial Plexus Palsy: Integrative literature review. *Journal of Clinical Medicine, 8*, 980, 1-12. doi:10.3390/jcm8070980
www.mdpi.com/journal/jcm

Friedman, M. Woods, J. & Salisbury, C. (2012). Caregiver coaching strategies for early intervention providers; Moving toward operational definitions. *Infant and Young Children, 25*, 62-82.

- Gans, D., Battistelli, M., Ramirez, M., Cabezas, L. & Pourat, N. (2013). Assuring children's access to pediatric subspecialty care in California. UCLA Center for Health Policy Research. 1-23. Retrieved from www.healthpolicy.ucla.edu
- Garne, K., Brødsgaard, A., Zachariassen, G. & Jane Clemensen, J. (2016). Telemedicine in neonatal home care: Identifying parental needs through participatory design. *Journal of Medical Internet Research Protocols*, (5), 3: e100, p. 1-8. doi: 10.2196/resprot.5467 <http://www.researchprotocols.org/2016/3/e100/>
- González-Espada, W., Hall-Barrow, J., Hall, W., Burke, B. & Smith, C. (2009). Achieving success connecting academic and practicing clinicians through telemedicine. *Pediatrics*, (123), 3, e476- 483
<http://pediatrics.aappublications.org/content/123/3/e476>
- Graham, F., Rodger, S., & Ziviani, J. (2009). Coaching parents to enable children's participation: An approach for working with parents and their children. *Australian Occupational Therapy Journal*, 56, 16-23. doi:10.1111/j.1440-1630.2008.00736.x
- Graham, F., Rodger, S. & Ziviani, J. (2010). Enabling occupational performance of children through coaching parents: Three case reports. *Physical and Occupational Therapy in Pediatrics*, 30, 4-15.
- Graham, F., Rodger, S., & Ziviani, J. (2013). Effectiveness of Occupational Performance Coaching in improving children's and mothers' performance and mothers' self-competence. *American Journal of Occupational Therapy*, 67, 10-18.
doi:10.5014/ajot.2013.004648

- Graham, F., Rodger, S., & Ziviani, J. (2014). Mothers' experiences of engaging in Occupational Performance Coaching. *British Journal of Occupational Therapy*, 77, 189-197. doi:10.4276/030802214x13968769798791
- Graham, F., Rodger, S., & Kennedy-Behr, A. (2017). Occupational Performance Coaching: Enabling caregivers' and children's occupational performance. In Rodger, S. & Kennedy-Behr, A. (2nd Eds.), *Occupation-centred practice with children: A practical guide for occupational therapists* (pp. 209-231). Chichester, UK: Wiley-Blackwell.
- Grillo, E. (2019). Building a successful voice telepractice program. *ASHA Wire, Journal Club Perspective*, 4 (1), 100-110. https://doi.org/10.1044/2018_PERS-SIG3-2018-0014
- Hall-Barrow, J., Hall, W. & Burke, B. (2009). Telemedicine and neonatal regionalization of care- ensuring that the right baby gets to the right nursery. *Pediatric Annals*, 38, 10, 557–561. Doi: 10.3928/00904481-20090918-02
www.PediatricSuperSite.com
- Hansen, M., & Klatt, T. (2015). The interstate medical licensure compact: what physicians should know. *South Dakota Medicine*, 68 (2), 81.
- Hielkema, T., Boxum, A., Hammer, E., La Bastide-Van Gemert, S., Dirks, T., Reinders-Messelink, H., Maathuis, C., Verheijden, J., Geertzen, J., & Hadders-Algra, M. (2019). LEARN2-MOVE 0-2 years, a randomized early intervention trial for infants at high risk of cerebral palsy: Family outcome and infant's functional

outcome. *Disability and Rehabilitation*, 1-9. DOI:

10.1080/09638288.2019.1610509

HealthyPeople.gov. (2017). Social determinants of health. Retrieved from

<https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>)

Heisler, E. (2013). Physician supply and the affordable care act. CRS Report for Congress, 7-7500(R42029), 1-29.

Hirko, K., Kerver, J., Ford, S., Szafranski, C., Beckett, J., Kitchen, C. & Wendling, A. (2020). Telehealth in response to the Covid-19 Pandemic: Implications for rural health disparities. *Journal of the American Medical Informatics Association*, 27, 11, 1816–1818. Retrieved from <https://academic.oup.com/jamia/article-abstract/doi/10.1093/jamia/ocaa156/5863253>

Jackson K., Scott K., Graff Zivin J, et al. (2008). Cost-utility analysis of telemedicine and ophthalmoscopy for retinopathy of prematurity management. *Archives of Ophthalmology* 126(4):493–499

Josiah Macy JR Foundation. (2016). Registered nurses: Partners in transforming primary care. Retrieved from http://macyfoundation.org/docs/macy_pubs/201609_Nursing_Conference_Executive_Summary_Final.pdf

Kameenui, E., & Carnine, D. (2001). *Effective teaching strategies that accommodate diverse learners*. Vol. 2nd ed. Paramus, NJ: Prentice Hall Inc.

- Kielhofner, G. (2008) *Model of human occupation: theory and application* (4th ed.).
Lippincott Williams & Wilkins
- Knowles, M (1980). *The modern practice of adult education: From pedagogy to andragogy*. Englewood Cliffs: Prentice Hall/Cambridge.
- LaBarbera, J., Ellenby, M., Bouressa, P., Burrell, J., Flori, H. & Marcin, J. (2013). The impact of telemedicine intensivist support and a pediatric hospitalist program on a community hospital. *Telemedicine and e-Health*, 19,10, 760-766. DOI: 10.1089/tmj.2012.0303
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P. & Letts, L. (1996). The Person-Environment-Occupation Model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63, 9–23.
- Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., & Rosenbaum, P. (2003). Factors affecting family-centred service delivery for children with disabilities. *Child*, 29, 357–366. Doi: 10.1046/j.1365-2214.2003.00351.x
- Little, L., Pope, E., Wallisch, A. & Dunn, W. (2018). Occupation-Based Coaching by means of telehealth for families of young children with autism spectrum disorder. *The American Journal of Occupational Therapy*, 72, 2, 7202205020p1-7202205020p7 <https://doi.org/10.5014/ajot.2018.024786>
- Lindgren, S., Wacker, D., Suess, A., Schieltz, K., Pelzel, K., Kopelman, T., Lee, J., Romani, P. & Waldron, D. (2016). Telehealth and autism: Treating challenging behavior at lower cost. *Pediatrics*, 137(Suppl. 2), S167-S175; DOI: <https://doi.org/10.1542/peds.2015-2851O>

- Little, L. M., Pope, E., Wallisch, A., & Dunn, W. (2018a). Occupation-based coaching by means of telehealth for families of young children with autism spectrum disorder. *American Journal of Occupational Therapy, 72*, 7202205020. Doi: 10.5014/ajot.2018.024786
- Little, L. M., Wallisch, A., Pope, E., & Dunn, W. (2018b). Acceptability and cost comparison of a telehealth intervention for families of children with autism. *Infants & Young Children, 31*, 275-286. Doi: 10.1097/IYC.0000000000000126.
- Mahnke, C., Jordon, C., Bergval, E. Person, D. & Pinsker, J. (2011). The Pacific Asynchronous TeleHealth (PATH) System: Review of 1,000 pediatric teleconsultations. *Telemedicine and e-Health, 17*, 1, 1-5. DOI: 10.1089/tmj.2010.0089
- Mahoney, Wheeden & Perales (2004). Relationship of preschool special education outcomes to instructional practices and parent–child interaction. *Research in Developmental Disabilities, 25*, 539–558.
- Marmot, M. & Wilkinson, R. (2006). *Social determinants of health* (2nd ed.) *International Journal of Epidemiology, 35* (4), 1111-1112. <https://doi.org/10.1093/ije/dyl121>
- McConnochie, K., Wood, N., Herendeen, N., ten Hoopen, C., Denk, L., Neuderfer, J. (2010). Integrating telemedicine in urban pediatric primary care: provider perspectives and performance. *Telemedicine Journal and eHealth 16*, (3), 280–288.
- McSwain, S. & Marcin, J. (2014) Telemedicine for the care of children in the hospital setting. *Pediatric Annals 43*(2), e44–e49.

Moffatt, J. J., & Eley, D. S. (2010). The reported benefits of telehealth for rural Australians. *Australian Health Review*, 34, 276–281.

National Advisory Committee on Rural Health and Human Services. (2015). Telehealth in rural America. Retrieved from <https://www.hrsa.gov/advisorycommittees/rural/publications/telehealthmarch2015.pdf>

Nationmaster. (2017). Geography > Land area > Square miles: Countries compared. Retrieved from <http://www.nationmaster.com/country-info/stats/Geography/Land-area/Square-miles>

Olson, C. & Thomas, J. (2017) Telehealth No longer an idea for the future. *Advances in Pediatrics*, 64, 347-370.

Yang, T. (2016). Health policy brief. Telehealth parity laws. *Robert Wood Johnson Foundation: Health Affairs*. Doi: 10.1377/hpb2016.12. Retrieved from http://healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicybrief_162.pdf

Ray, K., Demirci, J., Bogen, D., Mehrotra, A. & Miller, E. (2015). Optimizing telehealth strategies for subspecialty care: Recommendations from rural pediatricians. *Telemedicine and e-Health*, 21,8, 622-629. DOI: 10.1089/tmj.2014.0186

Robert Wood Johnson Foundation: Health Affairs. (2016). Telehealth parity laws. Ongoing reforms are expanding the landscape of telehealth in the US healthcare system, but challenges remain. *Health Policy Brief*. doi: 10.1377/hpb2016.12. Retrieved from http://healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicybrief_162.pdf

- Rush, D., Shelden, M. & Dunn, W. (2011). *The Early Coaching Childhood Coaching Handbook*. Brookes Publishing.
- Ryan, R. M. & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *55*, 68–78. doi:10.1037/0003-066X.55.1.68.
- Schoenwald, Sheidow, & Letourneau (2004). Toward effective quality assurance in evidence-based practice: Links between expert consultation, therapist fidelity and child outcomes. *Journal of Clinical Child and Adolescent Psychology*, *33*, 94–104.
- Shivji, S., Metcalfe, P., Khan, A. & Bratu, I. (2011). Pediatric surgery telehealth: patient and clinician satisfaction. *Pediatric Surgery International*, *27*, 523–526. DOI 10.1007/s00383-010-2823-y
- Siller & Sigman (2002). The behaviors of parents of children with autism predict the subsequent development of their children's communication. *Journal of Autism and Developmental Disorders*, *32*, 77–89.
- Smith, A. C., & Gray, L. C. (2009). Telemedicine across the ages. *Health Care*, *190*, 15–19.
- Smith, A. C., Scuffham, P. A., & Wootton, R. (2007). The costs and potential savings of a novel telepaediatric service in Queensland. *BMC Health Services Research*, *7*, 35.

- Thomson, K., Martin, G., Arnal, L., Fazzio, D. & Yu, C. (2009). Instructing individuals to deliver discrete-trials teaching to children with autism spectrum disorders: A review. *Research in Autism Spectrum Disorders*, 3, 590-606.
- Townsend, E. A. & Polatajko, H. J. (2007). *Enabling Occupation II: Advancing an occupational therapy vision for health, well-being, and justice through occupation*. Ottawa, ON: CAOT Publications ACE.
- Svorny, S., (2017). Liberating Telemedicine Options to Eliminate the State-Licensing Roadblock. *Policy Analysis*, 826, 1-21. Retrieved from file:///C:/Users/User/Documents/BU%20PP-OTD/Doctoral%20Project/Policies%20and%20frameworks/Liberating%20Telemedicine%202017.pdf
- The Patient Protection and Affordable Care Act, Publ. L. No. 111-148, 124 Stat. 119 (2010). <https://www.govinfo.gov/content/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf>
- Uscher-Pines, L., Mehrotra, A. & Bogen, D. (2017). The emergence and promise of telelactation. *American Journal of Obstetrics and Gynecology*, 217, 2, 176–179 <http://dx.doi.org/10.1016/j.ajog.2017.04.043>
- Vismara, L., McCormick, C., Young, G., Nadhan, A., & Monlux, K. (2013). Preliminary findings of a telehealth approach to parent training in autism. *Journal of Autism Developmental and Disorders* 43, 2953–2969. DOI 10.1007/s10803-013-1841-8

- Vismara, L. A., Young, G. S., & Rogers, S. J. (2012). Telehealth for expanding the reach of early autism training to parents. *Autism Research and Treatment*, 2012, 1–12. <http://dx.doi.org/10.1155/2012/121878>.
- Vismara, L. A., McCormick, C., Young, G. S., Nadhan, A., & Monlux, K. (2013). Preliminary findings of a telehealth approach to parent training in autism. *Journal of Autism and Developmental Disorders*, 43, 2953–2969. <http://dx.doi.org/10.1007/s10803-013-1841-8>.
- Wallisch, A., Little, L., Pope, E. & Dunn, W. (2019). Parent perspectives of an occupational therapy telehealth intervention. *International Journal of Telerehabilitation*, 11 (1), 15-22. Doi: 10.5195/ijt.2019.6274
- Williams, R., Biscaro, A. & Clinton, J. (2016). Relationships matter: How clinicians can support positive parenting in the early years. *Research in Autism Spectrum Disorders*, 23, 1–14.
- Wood, Luiselli, & Harchik (2007). Training instructional skills with paraprofessional service providers at a community-based habilitation setting. *Behavior Modification*, 31, 847–855.
- World Health Organization (2001). *International Classification of Functioning, Disability and Health Model (ICF)*. <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>

- Zielger, S., Dirks, T. & Hadders-Algra, M. (2019). Coaching in early intervention physical therapy: the COPCA program as an example of translation of theory into the practice. *Disability and Rehabilitation*, 41, 1846-1854.
- Ziegler, S., Mitteregger, E. & Hadders-Algra, M. (2020). Caregivers' experience with the new family-centred paediatric physiotherapy programme COPCA: A qualitative study. *Child Care Health Development*, 46, 28-36.
<https://doi.org/10.1111/cch.12722>
- Zielger, S. & Hadders-Algra, M. (2020). Coaching approach in early intervention and paediatric rehabilitation. *Developmental Medicine and Child Neurology*, 62, 569-574. DOI: 10.1111/dmcn.14493

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