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Unlimbited recreation: access to resources for improved wellness & wellbeing for individuals with ULL/D

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Unlimbited Recreation: Access to Resources for Improved Wellness & Wellbeing for
Individuals with ULL/D

A Doctoral Experiential Capstone Project Final Report
Presented to the Faculty of Western New England University

In Partial Fulfillment of the Requirements for the

Entry-Level Doctorate

in

Occupational Therapy

by

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July 2023

*Unlimbited Recreation: Access to Resources for Improved Wellbeing & Wellness for Individuals
with ULL/D*

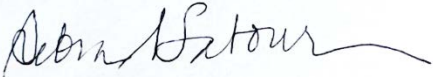
A Doctoral Experiential Capstone Project Final Report

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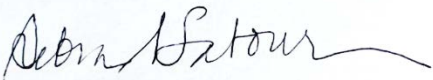
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Abstract

The doctoral experiential (DEx): *Unlimbited* Recreation explored the multifaceted aspects of upper limb loss and difference (ULL/D), focusing on recreational therapies and nonprofits' role in supporting affected individuals. This project highlighted the challenges individuals face with upper limb loss or difference and the therapeutic potential of recreational interventions. Additionally, it examined the contributions of nonprofits in providing comprehensive support and facilitating community integration for those individuals.

The experience of ULL/D could profoundly affect physical abilities, psychological well-being, and social interactions. Research has shown that recreational therapy is crucial in addressing these challenges, with adaptive sports, art-based activities, and leisure-based exercises as critical interventions. Recreational therapy enhanced physical function and mobility and fostered emotional resilience, self-confidence, and a positive body image among individuals with upper limb differences.

Nonprofit organizations have emerged as pivotal actors in providing essential services and resources to individuals with ULL/D. These organizations contributed to the accessibility of recreational therapy programs, financial assistance for prosthetics, counseling support, and peer mentorship. By forging partnerships with medical professionals, researchers, and recreational therapy experts, nonprofits created collaborative networks that maximized the impact of their interventions.

Keywords: upper limb loss, upper limb difference, recreational therapy, adaptive sports, psychological impact, rehabilitation, amputees, body image.

Introduction/ Background

Purpose

The *Unlimbited* Recreation program aimed to explore the multifaceted relationship between occupational therapists and nonprofit organizations in developing programs to enhance the well-being and functional independence of individuals with ULL/D and other diverse physical, cognitive, and psychosocial needs. By investigating the collaborative efforts between these entities, the project aimed to uncover the underlying factors that facilitated successful program development while also identifying potential barriers and challenges that might have hindered the effectiveness of these joint initiatives, such as lack of program funding.

Unlimbited Recreation aimed to analyze various collaboration models between occupational therapists and nonprofit organizations. This DEx capstone project sought to identify key focus areas in program development where occupational therapists and nonprofit organizations combined their expertise. These areas encompassed program development and implementation, accessibility and universal design, outcome measures and sustainability evaluations, and interprofessional teamwork with stakeholders and community members.

The occupational therapy student gathered insights from key stakeholders, including occupational therapists, nonprofit program executive directors, program board members, and other relevant parties at two nonprofit organizations: Destiny's Ride Therapeutic Program Inc. and Enhancing Skills for Life. By utilizing interviews and surveys, the research sought to understand the perspectives of the two nonprofit organizations regarding the benefits, challenges, and potential areas for improvement in their collaborative efforts.

The student evaluated the effectiveness of existing programs resulting from the collaboration between occupational therapists and nonprofit organization board members. They

measured outcomes related to functional improvements, executive director satisfaction, and program sustainability using quantitative and qualitative methods.

Understanding the barriers and facilitators that influenced successful collaboration was crucial. The student researcher identified challenges such as funding constraints, communication gaps, and resource limitations while highlighting facilitators such as shared vision, interdisciplinary teamwork, and innovative program design.

Unlimbited Recreation aimed to propose evidence-based best practice guidelines for occupational therapists and nonprofit organizations. These guidelines focused on enhancing collaboration in program development, optimizing outcomes, promoting resource efficiency, and ensuring long-term program sustainability.

Review of Literature:

Target Population Overview

In the United States, the number of people with limb loss is projected to increase to 3.6 million by 2050, highlighting the need for increased medical support and inclusive programs for this population (Ziegler-Graham et al., 2008). Limb loss can occur in two ways, congenital or amputation. *Amputation* is when the limb is removed due to a medical diagnosis or disease such as diabetes, trauma, or cancer. Congenital limb loss is present at birth, often with no one exact cause (Orthoinfo, 2020; Hanger Clinic, 2022). Those in the ULL/D population exhibit higher combined disability ratings than those with lower limb loss or difference, irrespective of whether the limb difference was congenital or traumatic (Hanger Clinic, 2022).

Studies have shown many gaps in care for individuals with ULL/D due to the need for equipped healthcare professionals to serve the population and regarding resources and interventions, specifically concerning the quality of life and overall well-being (Latour, 2019).

Many individuals' express feelings of isolation and experiences of social stigmas, which negatively impact their perception of outreach programs for ULL/D. However, programs like the *Unlimbited Wellness* © 2018 pilot program focused on providing health promotion and wellness to adults with upper-limb absences through education and meaningful occupation (Latour, 2019) is being created. This program aims to serve as a model for addressing individuals' physical and psychosocial needs with ULL/D, reducing disparities, and enabling participants to empower themselves (Latour, 2019).

By promoting increased participation in peer and outreach programs, occupational therapists can continue improving health and wellness outcomes and empowering participants through self-advocacy. According to the Amputee Coalition, about 1.9 million people have experienced limb loss currently residing in the United States (Amputee Coalition, 2019). Unfortunately, there is a lack of peer-reviewed research on the long-term effects of congenital upper limb absence, despite its prevalence of approximately one genetic limb difference per 500 births (Gielle et al., 2001). ULL/D can occur at any level, mainly if it is due to trauma, e.g., above (transhumeral) or below the elbow (transradial), partial hand (transcarpal), an elbow disarticulation or shoulder disarticulation, etc. (O'Sullivan et al., 2014). Nevertheless, research on the traumatic amputation population and their functional outcomes can be generalized to the congenital ULL/D population.

Most available data and resources group lower and upper limb loss together. It is essential to recognize that comparing individuals with ULL/D to those with lower limb loss is not equitable, as their problems and experiences differ significantly. Upper limb amputations occur at a 1:4 ratio to lower limb amputation (Orr, 2020). It is essential to differentiate between these two populations due to the significant differences in functional limitations, rehabilitation

needs, and psychosocial impacts associated with each type of limb loss. Lower limb loss affects mobility and ambulation, whereas upper limb loss impacts dexterity and fine motor skills.

Research has shown that distinguishing between lower and upper limb loss allows for targeted interventions, improving functional outcomes and quality of life. For instance, studies have highlighted the importance of gait training and prosthetic fitting for lower-limb amputees to enhance mobility and reduce the risk of secondary health issues (Kevin Wong et al., 2016). On the other hand, research has emphasized the significance of adaptive devices and therapeutic interventions for upper limb amputees to improve functional independence in daily activities (Melton, 2017).

By understanding these differences, healthcare professionals can provide personalized care, support, and resources, addressing the specific physical and emotional needs of individuals with lower or upper limb loss and difference. Moreover, this differentiation aids in optimizing the allocation of resources and promoting greater inclusivity and accessibility for the limb loss community. An in-depth literature review for this project can be found in Appendix A.

Resource Availability and Barriers

Several available resources specifically cater to individuals in the upper limb loss and difference (ULL/D) populations, providing support, information, and services to address their unique needs. These resources include the Amputee Coalition, Enhancing Skills for Life, Challenged Athletes Foundation, the *Unlimbited* Wellness Program © 2018, and many more. These resources offer a range of services, from emotional support and education to access to advanced prosthetic technologies and adaptive sports opportunities. They are vital in empowering individuals with upper limb loss and fostering community and inclusion within the ULL/D population.

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However, there are several gaps in care for individuals with upper limb loss and difference (ULL/D), reflecting areas where further improvements and attention are needed to enhance their overall well-being and quality of life. Some of the notable gaps in care include psychological support, prosthetic access and affordability, adequate rehabilitation services, and, finally, community support and peer mentorship programs. Addressing these gaps requires a multidisciplinary approach involving healthcare professionals, researchers, policymakers, and nonprofit organizations, focusing on delivering comprehensive, person-centered care for individuals with ULL/D.

Strong peer support networks can significantly impact individuals with ULL/D by providing valuable insights, coping strategies, and emotional encouragement. Establishing community support programs may require further attention (Adams et al., 2015). Individuals with ULL/D may face emotional challenges related to body image, self-esteem, and adjustment to limb loss. Access to mental health services and specialized counseling tailored to the unique needs of this population is often limited. In addition, the lack of awareness about the challenges faced by individuals with ULL/D can lead to misconceptions and stigmatization. Raising public awareness and promoting inclusive attitudes are essential to foster a supportive environment for this population. Specific programs like Enhancing Skills for Life focus on socialization, sharing tips and tricks, and building supportive friendships within the limb loss community. They also financially support individuals missing both arms to attend the Skills for Life: Bilateral Upper Limb Loss Workshop (Enhancing Skills for Life, 2023). While both organizations have already made significant impacts, further program development is necessary to increase their effectiveness in serving their targeted population. An in-depth needs assessment for the identified target population can be found in Appendix B.

Theoretical Framework

The PEOP model, which stands for Person-Environment-Occupation-Performance, is a widely used occupational therapy framework that takes a holistic approach to understanding and addressing the needs of individuals in various populations, including those in the upper limb loss and difference community. The model emphasizes the interplay between the person's abilities, the environment they interact with, and the meaningful occupations or activities they engage in. For individuals with ULL/D, the PEOP model can be effectively applied to guide the assessment, intervention, and treatment process.

The PEOP model recognizes the individual as the central focus of the intervention. In the context of ULL/D, this entails understanding the person's physical abilities, psychological well-being, and social context. Occupational therapists assess the person's residual limb function, prosthesis use, functional limitations, and personal goals and preferences related to daily activities (Baum et al., 2015).

This model acknowledges the significance of the environment in influencing an individual's participation and performance. In the case of ULL/D, the environment may include physical barriers and facilitators, accessibility of assistive technologies and prosthetics, and social support networks. Occupational therapists consider environmental factors when planning interventions to promote optimal engagement and function (Eichberg et al., 2017).

Occupations refer to the meaningful activities' individuals engage in daily. For those with ULL/D, these occupations can range from basic self-care tasks to complex activities requiring dexterity and fine motor skills. The PEOP model directs occupational therapists to address these meaningful activities in their treatment plans, focusing on functional independence and participation (Baum et al., 2015).

Performance in the PEOP model refers to an individual's ability to carry out meaningful activities successfully. In the context of ULL/D, this includes activities like dressing, cooking, writing, and participating in hobbies. Occupational therapists work on enhancing performance through adaptive techniques, assistive devices, and tailored interventions (AOTA, 2020).

By adopting the PEOP model, occupational therapists can develop comprehensive and person-centered interventions for individuals with ULL/D. The model allows them to consider each person's unique needs and goals, the impact of the environment, and the importance of meaningful activities to promote functional independence and overall well-being within the ULL/D community.

Doctoral Experiential Overview

Project Overview and Deliverables

The overarching goal of this DEx project was to engage executive directors and board members of nonprofit organizations that provided recreational therapy programs for individuals with ULL/D and other conditions. The student researcher worked closely with executive directors of two nonprofit organizations to create site-specific resources to increase program development, provide grant and funding education, and facilitate community outreach.

As part of *Unlimbited Recreation*, the student researcher partnered with *Destiny's Ride Therapeutic Program Inc.* This nonprofit organization provides a unique equestrian experience for individuals with ULL/D and other disabilities (Destiny's Ride, 2023). With the support of Jodie O'Connell Ponkos, COTA, the Founder and Executive Director of *Destiny's Ride*, the researcher was provided with the necessary resources for program development, including access to riding lessons and clinical consultation from a certified occupational therapy assistant and

licensed PATH riding instructor. Jodie O'Connell Ponkos was the site mentor and consultant for Destiny's Ride Therapeutic Program Inc.

One of the primary resources provided by this doctoral experiential project was a grant funding database and a nonprofit resource manual that was developed in summation of the scholarly component of the Core & More program. These resources guided board members and executive directors of organizations such as Destiny's Ride. The resource manual was essential for program development in nonprofit organizations as it provided a comprehensive and accessible guide to support the entire process. The manual offered valuable insights, best practices, and standardized procedures for effective program planning, implementation, and evaluation. It ensured consistency and uniformity in program development across the organization, reducing the risk of errors and enhancing its ability to achieve its mission (Laughlin, 2007).

The resource manual facilitated efficient resource allocation by providing information on available resources, potential funding sources, and cost-effective strategies. These resources enhanced the program's sustainability and impact, allowing nonprofits to maximize their resources and achieve better outcomes (Laughlin, 2007). Additionally, the manual supported capacity building among nonprofit staff and volunteers by offering training materials, tools, and templates to improve their program development and management skills. This empowered personnel to implement programs more effectively and confidently (Smith & Stevens, 2021). Overall, the well-structured resource manual streamlined program development efforts preserved institutional knowledge, and enhanced nonprofit organizations' overall effectiveness and impact in fulfilling their mission.

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The research also worked closely with Shawn Swanson Johnson, OTR, the site mentor for Enhancing Skills for Life. This program served individuals with bilateral upper limb loss or more with a focus on socialization, sharing tips and tricks, and building supportive friendships. They also financially supported individuals missing both arms to attend the Skills for Life: Bilateral Upper Limb Loss Workshop (Enhancing Skills for Life, 2023). The student researcher provided a series of deliverables for this specific program to increase funding resources and promote program development. The first resource provided was a grant database that aimed to be a centralized repository of information on available grants and funding opportunities that best fit the needs of Enhancing Skills for Life. It provided a comprehensive and up-to-date list of grants from various sources, including government agencies, foundations, and corporations, streamlining the search process for potential funding opportunities. Nonprofits such as Enhancing Skills for Life could utilize this database to identify suitable grants, access application guidelines, and increase their chances of securing financial support for their projects and initiatives.

In addition to these deliverables, the student research also worked to create program outlines to increase program development for Enhancing Skills for Life, creating a peer connections program outline and initial survey, a monthly Zoom meet-up outline and etiquette tip sheet, helping to update and produce monthly newsletter content, and finally creating occupational therapy based clinical content tip sheets and booklets.

Community Experiential Components: Needs Assessment

The doctoral experiential (DEx) requires students to complete a needs assessment and other daily activities required for Destiny's Ride and Enhancing Skills for Life. In addition to an updated needs assessment on the target population, the researcher completes community

experiential activities. These activities included developing, photographing, and editing digital content pieces (exercise manual, newsletters, tip sheets, and a product booklet). During the first few weeks of the DEx project, the researchers completed a weeklong upper limb rehabilitation course. The course included four quizzes and terminology assignments to understand the ULL/D population, the role of occupational therapy throughout the evaluation, assessment, and intervention process, and identify the different types of prosthetic technology available to this population. See Appendix C for Course Certification

The researcher also attended an educational webinar held by John Hopkins covering topics such as clinical anaplastology, realities of overuse injuries, digital technology resources, skin complications, and surgical technology advancements. Attending this webinar supplemented the researcher's knowledge and understanding of the population and allowed them to network with specialized providers. Additionally, the student research participated in observing activities at Destiny's Ride Therapeutic Program Inc., such as groundwork, riding lessons, and monthly board meetings to guide the program development and gain the necessary experience with horses, participating riders, and board members.

Scholarly Component: Unlimbited Wellness Program © 2018 Core & More Program

Specific aspects of this project were intended to expand on the *Unlimbited Wellness Program © 2018* developed by Debra Latour, PP-OTD, M. Ed., OTR/L. The *Unlimbited Wellness Program © 2018* educates and empowers individuals with ULA (Latour, 2019). This extension of the *Unlimbited Wellness program © 2018* focuses on creating a Core & More program tailored to the needs of horseback riders in equine therapy programs. Core strength and balance are crucial for horseback riding, providing stability, effective communication, and improved riding performance. A strong core aids in maintaining an upright posture, while

balance enables the rider to stay centered and aligned with the horse's motion. Promoting a stronger core and increased balance enhances safety, supports the horse's movement, and fosters a harmonious rider-horse connection (Stafford & Oliver, 1991).

The Core & More programs involve an instructional manual that includes functional fitness images and exercise descriptions. In addition to the core and balance exercises provided, the student researcher also created a groundwork program. Groundwork refers to exercises and activities performed on the ground to establish a strong foundation of communication, trust, and respect between the horse and the handler. Groundwork typically includes activities such as leading the horse, yielding hindquarters and forequarters, backing up, desensitization to various stimuli, and establishing boundaries for personal space (Smith, 2007).

While this program was created specifically for individuals of all abilities participating in equine therapy, it also relates to the population served explicitly by the Unlimited Wellness Program © 2018, individuals with ULL/D. Core strength and balance are crucial in the functional abilities and overall well-being of individuals with upper limb loss and difference (ULL/D). As individuals with ULL/D rely more on their remaining upper limb and core for stability and compensatory movements, having a solid core and good balance becomes essential for performing daily activities and engaging in physical tasks. Core strength and balance are essential for rehabilitation and functional training for individuals with upper limb loss and difference. These factors improve compensatory movements, enhance prosthetic control, enable daily activities, facilitate mobility, and promote overall well-being. Incorporating core and balance exercises into rehabilitation and ongoing training can significantly improve functional outcomes and overall quality of life for individuals with ULL/D.

Many individuals with ULL/D use prosthetic devices to regain some upper limb functionality. Core strength stabilizes the body while operating the prosthesis, enabling smoother and more coordinated movements (Resnik, 2017). Individuals with ULL/D who use a prosthetic device and those who do not often adapt by using their residual limb to perform tasks requiring dexterity and precision. A strong core allows for better stabilization during these compensatory movements, facilitating improved control, accuracy, and better posture and body alignment, decreasing the risks of overuse injuries (Gajewski et al., 2006).

Discussion and Recommendations

Results

Four board members from Destiny's Ride were invited to participate in a survey about program needs and potential DEx deliverables. Image 1 summarizes the participants' responses on what was needed to impact their program significantly. Image 2 summarizes what resource participants thought would be essential to increase program development. All four participants attended the first board meeting to discuss these outcomes, and all four attended the closing board meeting. Lastly, two (both site mentors) participants completed the student satisfaction survey to rate and discuss their overall satisfaction with their deliverables and student research performance. These results can be seen in Image 3.

Image 1: Board Member Responses

What would make the greatest difference in helping Destiny's Ride get better at what it does? [Copy](#)

5 responses

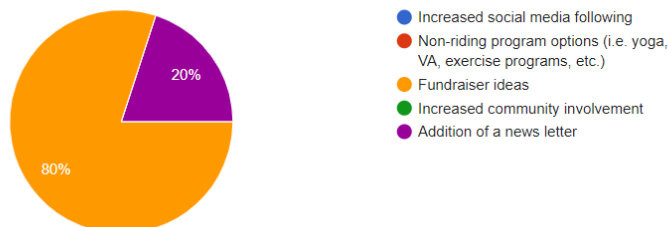


Image 2: Board Member Responses

In your opinion what resource is most important for me to provide for Destiny's Ride to help continue to promote increased program development? [Copy](#)

5 responses

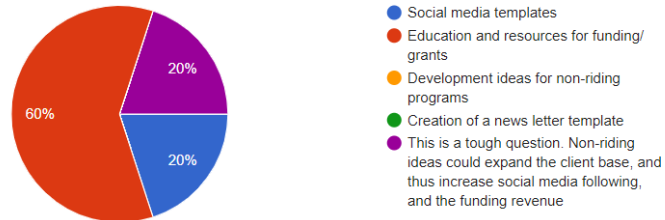
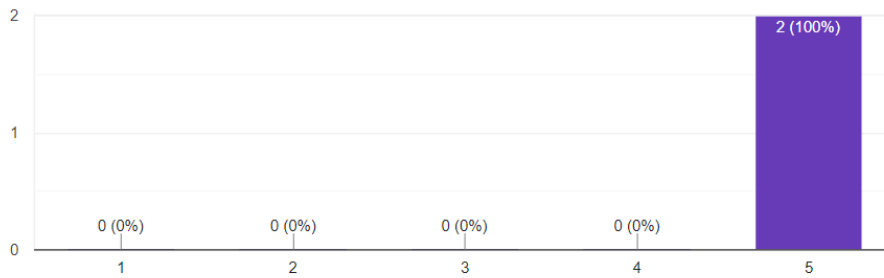


Image 3: Student Satisfaction Survey Responses

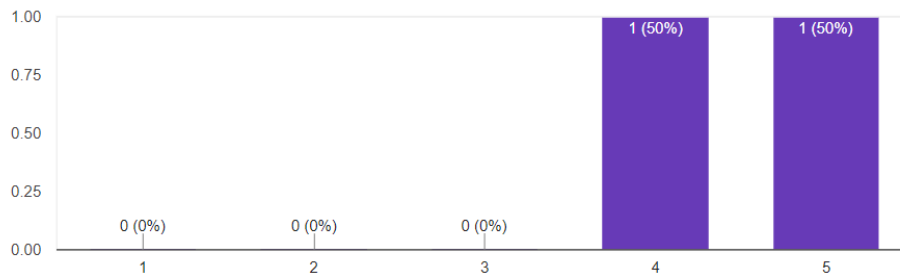
How satisfied are you with the outcomes of this project? [Copy](#)

2 responses



Do you feel that the resources provided are sustainable for future use? [Copy](#)

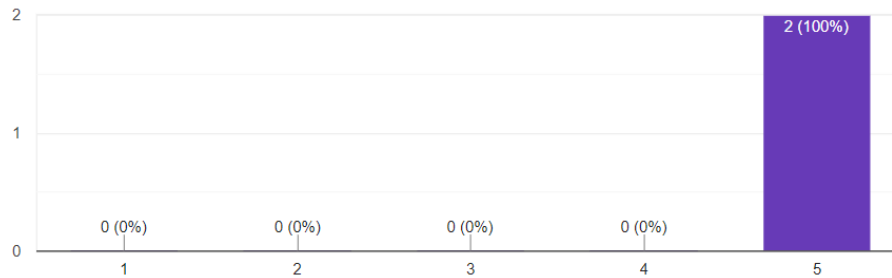
2 responses



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Do you feel as though your programs resources have increased as a result of the OTD students efforts? [Copy](#)

2 responses



What can the student improve on for future interprofessional projects?

2 responses

hard question to answer as all aspects of Alyssa's involvement were positive

Team building and motivating team members in order to solicit timely feedback and hold others accountable rather than accomplishing everything themselves, delegation and follow up are important skills to develop and enhance for inter-professional projects

Discussion and Recommendations

Results

Four board members from Destiny's Ride were invited to participate in a survey about program needs and potential DEx deliverables. Image 1 summarizes the participants' responses on what was needed to impact their program significantly. Image 2 summarizes what resource participants thought would be essential to increase program development. All four participants attended the first board meeting to discuss these outcomes, and all four attended the closing board meeting. Lastly, two (both site mentors) participants completed the student satisfaction survey to rate and discuss their overall satisfaction with their deliverables and student research performance.

RESOURCES FOR IMPROVED WELLNESS & WELLBEING FOR INDIVIDUALS WITH ULL/D

Nonprofit recreational therapy programs like Enhancing Skills for Life and Destiny's Ride are vital for individuals with upper limb loss and difference, providing numerous benefits for physical, emotional, and social rehabilitation. These programs offer adapted activities in a supportive environment, enhancing physical functionality and emotional well-being.

Occupational therapists play a crucial role by conducting holistic assessments, developing personalized program development tools, collaborating with interprofessional members, and adapting activities to accommodate participants' needs. They can promote these programs by collaborating with organizations, raising awareness, conducting research, and attracting support, empowering participants to embrace life fully. These programs are a lifeline, offering a pathway to improved well-being and quality of life for those facing upper limb challenges.

The Executive Directors of both organizations found the resources provided accessible, informative, and sustainable. Likewise, all the board members appreciated the program resources and stated interest in building them further to promote program development.

Recommendations for Future

To foster growth and effectiveness in nonprofit recreation therapy programs like Destiny's Ride and Enhancing Skills for Life, key focus areas include strategic planning, collaboration, fundraising, and professional development. By following the resource manual and grant funding database recommendations, these programs can thrive and have a positive impact on their communities. Building resilience, sustainability, and credibility is essential. The suggested strategies encompass developing clear visions, engaging with the community and stakeholders, seeking collaborations, diversifying funding sources, implementing program evaluation, advocating for recognition, investing in staff training, embracing innovation, promoting inclusivity, and continuously seeking feedback for improvement. Successfully

applying these approaches will lead to improved outcomes for participants and contribute to the advancement of therapeutic recreation.

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Appendix A

Review of Literature

I. Review of Literature

"A non-profit organization is a group organized for purposes other than generating a profit and in which no part of the organization's income is distributed to its members, directors, or officers" (Cornell Law School, 2023). Non-profit organizations have seen increased prominence in the last two decades due to the availability of online platforms. Online giving has generated substantial donations for non-profits, and social media and technology have facilitated program promotions (Non-profit Hub, 2023). However, not all programs have equal access to these platforms and rely on research to find grants and funding sources. Therefore, the primary goal of non-profit organizations is to provide a safe environment and resources to promote engagement and participation in activities and events.

This doctoral experiential capstone focuses on program development for non-profit therapeutic recreation organizations specifically catering to individuals with upper limb absence

(ULA). These organizations aim to sponsor, host, and participate in events promoting rehabilitating individuals affected by upper limb loss (ESFL, 2023). While therapeutic recreation programs are available for individuals with limb absence, few are explicitly geared towards those with ULA, which can present congenitally or through acquisition.

Most available data and resources tend to group lower and upper limb loss. Still, it is essential to recognize that comparing individuals with upper limb loss to those with lower limb loss is not equitable, as their problems and experiences differ significantly. Individuals with any limb loss often experience depression and financial hardships, and those with ULL/D have substantially higher medical expenses than those without limb loss (Hanger Clinic, 2021). The number of people with limb loss is projected to increase to 3.6 million by 2050, highlighting the need for increased medical support and inclusive programs for this population Ziegler-Graham et al., 2008).

II. Needs Assessment

Many non-profit organizations integrate recreational activities and therapy into their programs to promote client-centered care and increase participation in meaningful activities. Occupational Therapy and Recreational Therapy share philosophical roots in the belief that health and quality of life emerge through engaging in a healthy variety of meaningful activities. Occupational therapists (OTs) support their clients in meaningful life occupations by increasing participation through habilitation, rehabilitation, and promotion of health and wellness (AOTA, 2014b, p.S1). Recreational Therapy aims to restore, remediate, and rehabilitate individuals' functioning and independence in life activities, promoting health and wellness while reducing activity limitations caused by illnesses or disabling conditions (ATRA, 2023).

Occupational therapists play a crucial role in advocating for the needs of non-profit organizations, promoting the creation of therapeutic recreation programs, and enhancing participants' overall quality of life by ensuring accessibility to meaningful activities. The American Occupational Therapy Association (AOTA) works to advance occupational therapy through standard-setting, advocacy, education, and research, supporting its members and the public. OTs encompass various roles beyond clinical treatment care, including educators, motivators, care coordinators, confidants, and advocates for patients and places of work such as non-profit organizations (Stover, 2015). Research has highlighted the overlap between the health and legal fields, emphasizing the importance of OTs' education in working closely with non-profit organizations, providing grant and funding information, resources, interdisciplinary relationships, and more.

III. Community Profile

The *Unlimbited* Wellness pilot program focused on providing health promotion and wellness to adults with upper-limb absences through education and meaningful occupation (Latour, 2019, p. 253). The program specifically targeted adults with congenital ULA and secondary conditions, including psychosocial impacts. By utilizing telehealth, the *Unlimbited* Wellness program aimed to improve participants' understanding of physical and psychosocial health conditions related to ULA, teach strategies for self-advocacy, and provide peer support (Latour, 2019, p. 250).

Many program participants expressed feelings of isolation and experiences of social stigmas, which negatively impacted their perception of outreach programs for ULA. However, the program successfully addressed these challenges, improving health and wellness outcomes and empowering participants through self-advocacy. In addition, the *Unlimbited* Wellness

program serves as a model for addressing individuals' physical and psychosocial needs with ULA, reducing disparities, and enabling participants to empower themselves (Latour, 2019, p. 254).

Destiny's Ride, a non-profit organization in New York, provides equestrian experiences for individuals with ULA and other disabilities (Destiny's Ride, 2023). Enhancing Skills for Life, based in Texas, aims to foster socialization, support friendships, and financially support individuals with bilateral upper limb loss to attend the Skills for Life: Bilateral Upper Limb Loss Workshop (Enhancing Skills for Life, 2023). Both organizations require further program development to increase their impact on the targeted population. Additionally, implementing a telehealth program, such as Unlimbited Wellness, could facilitate communication between program directors, board members, and non-profit organizations, allowing for discussions on improvement areas and necessary resources.

Appendix B

Needs Assessment

I. Problem/Unmet Need

Upper limb absence (ULA), also known as upper limb deficiency, can occur either congenitally or as a result of acquired causes. When conducting a literature review and searching public organizations, acquired and congenital ULA are often categorized alongside lower limb loss. However, it is essential to note that while they share the common factor of limb loss, comparing individuals with upper limb loss to those with lower limb loss is not feasible due to the fundamental differences in their challenges and experiences.

Research indicates that 36% of individuals with any limb loss experience depression and financial hardships. Moreover, the medical costs for individuals with upper limb loss or

deficiency are estimated to be \$150,000 higher than those without (Hanger Clinic, 2021).

However, with the projected increase in the number of people with limb loss to 3.6 million by 2050 (Ziegler-Graham et al., 2008), there is a pressing need for expanded medical support and inclusive programs for individuals in this population.

II. Target Population

This doctoral experiential capstone aims to develop programs for non-profit therapeutic recreation organizations catering to individuals with upper limb absence (ULA). These organizations seek to sponsor, host, and participate in events and activities that promote rehabilitating individuals affected by upper limb loss (ESFL, 2023). While several therapeutic recreation programs exist for individuals with limb absence, there is a notable lack of programs explicitly tailored to those with ULA.

According to Cornell Law School (2023), a non-profit organization is a group organized for purposes other than generating profit, and none of its income is distributed to its members, directors, or officers. Non-profit organizations have gained prominence in the last two decades, primarily due to the availability of online platforms. For instance, online giving generated \$2.1 billion in donations for non-profits in 2012 and has continued to grow since (Non-profit Hub, 2023).

The rise of social media and technology in the early 2000s has significantly increased the accessibility of program promotions. However, not all programs have equal access to these platforms and rely on research to find grants and other funding sources for program development. Therefore, the primary goal of many non-profit organizations is to provide a safe

environment, equipment, and resources to the target population, fostering engagement and participation in relevant activities and events.

III. Literature Review

The existing research primarily focuses on prosthetic use and specific conditions related to upper limb functioning, such as strokes or traumatic amputations, as observed through an extensive literature search. However, it is worth noting that congenital and traumatic amputations are often grouped in research. Unfortunately, there is a lack of peer-reviewed research on the long-term effects of congenital upper limb absence, despite its prevalence of approximately one genetic limb difference per 500 births (Gielle et al., 2001). Most of the published literature pertains to the effects of traumatic amputations. Nevertheless, research on the traumatic amputation population and their functional outcomes can be generalized to the congenital ULA population, except for the experiences of phantom limb pain primarily reported by those with traumatic limb loss (Montoya et al., 1998). For instance, individuals with upper limb amputations exhibit higher combined disability ratings than those with lower limb amputations, irrespective of whether the limb difference was congenital or traumatic (Fitzgibbons & Gleb, 2015).

A study involving an online questionnaire completed by participants with congenital and acquired mobility issues examined life satisfaction in self-esteem, disability identity, and disability self-efficacy. The findings indicated greater life satisfaction among individuals with acquired conditions. In addition, they emphasized the importance of fostering disability self-concept and involvement in the disability community, as normalizing individuals with disabilities can have long-term effects (Bogart, 2014).

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Further investigation into the lack of support and programs available in the New England area revealed the implications of this gap. DeLuca et al. (2021) developed a survey to assess the highest priority areas for physical and mental health among individuals with ULA. The survey participants ranked priorities such as phantom limb pain, eradication of chronic residual pain, strength and balance, counseling, exercise, peer support groups, and techniques for better sleep. These findings can be utilized to develop meaningful programs for the ULA population. Another study by Marzen-Groller & Bartman (2005) implemented a support group for amputees, demonstrating that participants experienced a sense of belonging as one of the most desired outcomes.

Similarly, a program designed to promote physical and mental wellness, social support, and community development for individuals with upper limb absence showed increased health outcomes in terms of psychological and physical well-being (Latour, 2019). These sources emphasized the importance of condition-specific community engagement and informed education to ensure positive health outcomes for individuals with ULA. Unfortunately, there are limited options for programs that offer these services. Additionally, individuals who acquired amputations expressed dissatisfaction with the level of education provided by acute care health professionals (Marzen-Groller & Bartman, 2005).

Many non-profit organizations incorporate recreational activities and therapy into their programs to promote client-centered care and increase participation in meaningful activities. Both occupational therapy and recreational therapy share the belief that health and quality of life emerge when individuals regularly engage in a healthy variety of meaningful activities (U Health, 2023). Occupational therapists (OTs) can collaborate with these non-profit organizations to advocate for the needs of individuals with ULA, promote the development of therapeutic

recreation programs, and enhance the overall quality of life and accessibility to meaningful activities. In addition, the American Occupational Therapy Association (AOTA) is dedicated to advancing occupational therapy's quality, availability, use, and support through various means, including standard-setting, advocacy, education, and research (AOTA, 2014a).

OTs possess a diverse range of roles beyond clinical treatment care, including education, motivation, coordination of care, being a confidant, and advocating for patients and organizations such as non-profits. Studies have demonstrated that practitioners recognize the overlap between the health and legal fields, encompassing standards of care, practice guidelines, and coverage limitations or expansions imposed by legislation or payer rules (Stover, 2015). Given this knowledge, OTs can work closely with non-profit organizations, providing essential information on grants, funding, resources, interdisciplinary relationships, and more.

IV. Resources Availability

The Unlimbited Wellness Program © 2018, as described by Latour (2019), aimed to provide health promotion and wellness opportunities to adults with upper-limb acquired loss or congenital differences. This program focused on telehealth to enhance understanding of physical and psychosocial health conditions related to ULA, strategies for self-advocacy, and access to peer support. Participants reported feelings of isolation and experiences of social stigmas towards outreach programs for ULA. Nevertheless, the program achieved its goal, as indicated by participant survey responses. Participants were empowered through newly acquired self-advocacy methods, and the physical and psychosocial needs of Americans with ULA were addressed, reducing the existing disparity (Latour, 2019).

Destiny's Ride is a non-profit organization in New York that offers a unique equestrian experience for individuals with ULA and other disabilities (Destiny's Ride, 2023). This program provides opportunities for recreational and meaningful activities such as equine therapy, Special Olympics, and life coaching. Similarly, Enhancing Skills for Life, based in Texas, focuses on socialization, sharing tips and tricks, and building supportive friendships within the limb loss community. They also financially support individuals missing both arms to attend the Skills for Life: Bilateral Upper Limb Loss Workshop (Enhancing Skills for Life, 2023). While both organizations have already made significant impacts, further program development is necessary to increase their effectiveness in serving their targeted population. Additionally, the Unlimbited Wellness Program © 2018 can be used to implement a telehealth program, allowing program directors and board members to discuss areas of improvement and the resources that need to be provided.

V. Barriers

Studies have shown that individuals with ULA often choose not to participate in activities or support groups due to various barriers. Lack of participation can be attributed to the failure to address participants' changing needs, irrelevant or non-patient-driven meeting content, limited focus on increasing functionality and familiarity with prosthetic technology, and lack of technology support (Nathan & Winkler, 2019). In addition, environmental barriers, such as climate, physical environment, and income, have also been identified as common obstacles to participation in sports, recreation, leisure, and employment (Gallagher et al., 2011).

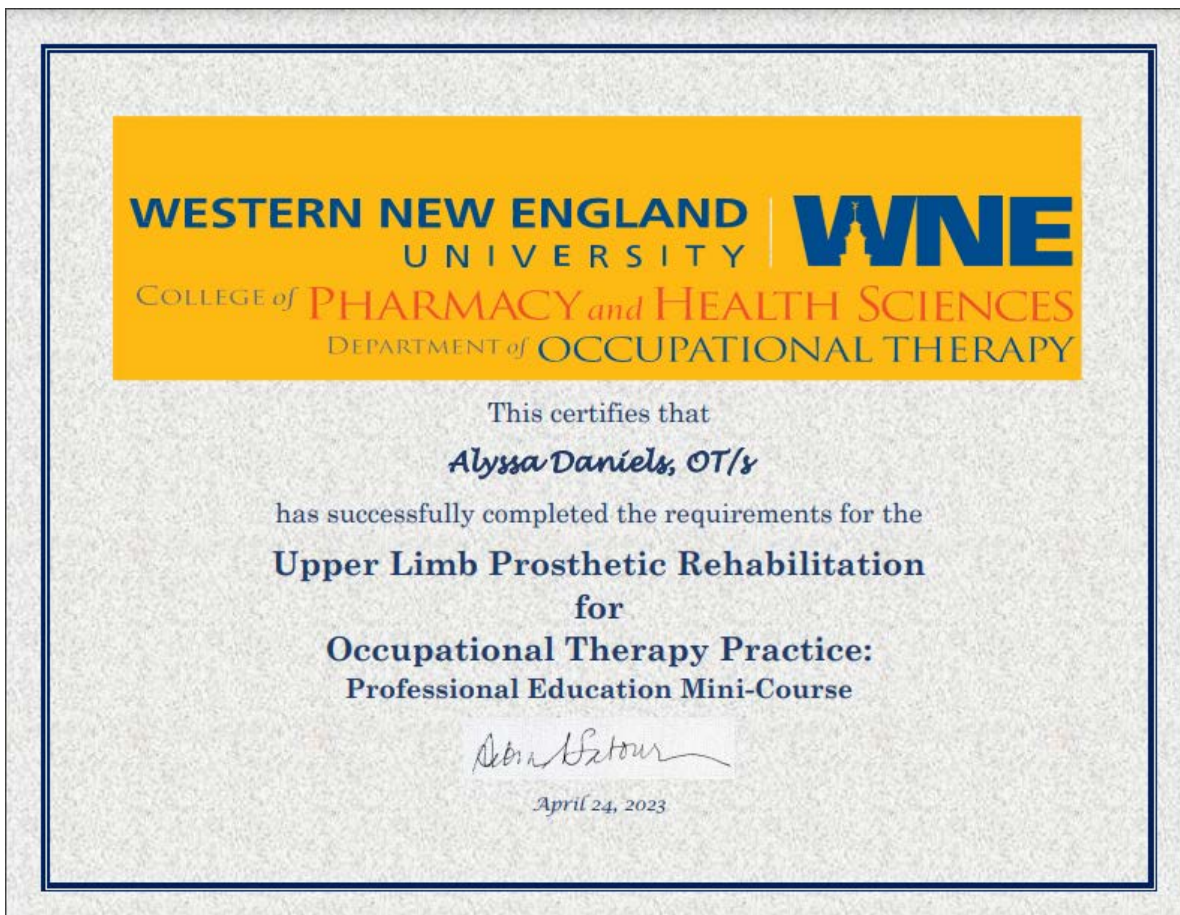
Self-perceived abilities, coping with stigma, and family socioeconomic status significantly influence participation. For example, customized prostheses, positive self-perception and self-talk, supportive family, friends, and coaches, love for sports and sports culture, physical and

social benefits of sports participation, and external supports like charitable organizations were identified as facilitators of participation (Ahmed & Lamy et al., 2018).

In the context of telehealth, barriers exist as well. Gajarawala and Pelkowski (2020) pointed out that telehealth cannot conduct physical examinations, which can impact prosthetic use and hinder the assessment of specific physical barriers. Additionally, practitioners may have licensing issues, as occupational therapists must be licensed in multiple states to serve the ULA population. Healthcare providers and patients can also encounter reimbursement challenges, as insurance policies and reimbursement policies differ between states. Moreover, not all individuals can access the necessary technology and internet connection for telehealth platforms (Gajarawala & Pelkowski, 2020).

Appendix C

Certificate of Upper Limb Rehabilitation Course Completion



Appendix D

IRB Form

**WESTERN NEW ENGLAND UNIVERSITY
INSTITUTIONAL REVIEW BOARD (IRB) SUBMISSION FORM
FOR PROPOSAL TO USE HUMAN PARTICIPANTS IN RESEARCH
FWA00010736**

Last Modified September 21, 2022

Information regarding the annual meeting schedule of the Institutional Review Board, submission deadlines and requirements, and contact information may be found on the IRR section of the Academic Affairs website located at: <https://www1.wne.edu/academic-affairs/institutional-review-board.cfm>

Date of Application:
(MM/DD/YYYY)

05/02/2023

1. Responsible
Project Investigator
*(Note: students/
residents cannot serve
as PIs):*

Dr. Debra Latour PP-OTD, M.Ed., OTR/L

Phone No.: 413-782-1449

Address (Campus
address, including
box #, if available):

Blake Law School Room 220
1215 Wilbraham Rd
Springfield, MA 01119

E-mail: debra.latour@wne.edu

2. Investigator (e.g.,
Graduate Student)
*(Note: Please list any
additional investigators
in Appendix):*

Alyssa K. Daniels

Phone No.: (203)537-1865

Address (Campus
address, including
box #, if available):

10 Keats Road
Meriden, CT 06451

E-mail: alyssa.daniels@wne.edu

3. Collaborations:
Does this project involve
any collaborators not
part of the faculty/staff at
WNEU?

No

Yes

Please specify:

Jodie Ponkos O'Connell, COTA
Executive Director of Destiny's
Ride and Shawn Swanson
Johnson, OTR Executive

4. Title of Project:

UnLIMBited Recreation: Access to Prosthetic Technology and Services for Improved
Wellness & Wellbeing

5. Submission Type:

New

Renewal

Amendment

6. Anticipated Project Duration:

From MM/YYYY: 04/2023

To MM/YYYY: 04/2024

NOTE: Any research project that undergoes full board review and continues for longer than one (1) calendar year requires annual renewal.

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7. Non-Technical Synopsis:
(Please provide a brief abstract in non-scientific terms.)

This doctoral experiential project aims to create a funding and resource manual based on specific needs for Destiny's Ride, a non-profit organization developing therapeutic recreation programs for individuals with upper limb absence (ULA) and other disabilities. This manual will include aspects of funding/ grant information, program improvement interventions, education on devices and social media use, and informational newsletters templates to help further develop their existing therapeutic recreation program.

8. Background:
(Please provide a brief narrative review of the literature and basis of the study.)

This doctoral experiential capstone project aims to provide a manual containing information regarding funding, resources, technology/ social media use, etc. ULA occurs in two ways: congenital or acquired. Acquired and congenital ULA is often categorized as a lower-limb loss when conducting a literature review and searching public organizations. Although they share the common denominator of limb absence, it is impossible to compare people with upper versus lower limb loss equally, as the problems and experiences are fundamentally different. For example, 36% of individuals with limb loss

9. Objective:
(Briefly state the objective of the research.)

UnLIMBited Recreation is a program to serve non-profit organizations that serve those in the upper limb absence (ULA) population. This program will work with program directors and stakeholders to access therapeutic programs to help promote increased funding and improve the program's overall quality. The occupational therapy student will perform exhaustive research and work with stakeholders from Destiny's Ride to determine

10. Type of research participant (Include all that apply.) **Indicate the approximate number in each category.**

Undergraduate WNE student (18 years old or older) #

Undergraduate WNE student (less than 18 years old) #

Graduate or Law WNE student #

WNE employee (18 years old or older) #

WNE employee (less than 18 years old) #

Minor not otherwise specified (less than 18) #

Off-campus participants (specify including age and #)

Special population (e.g., prisoner, pregnant, disabled) (specify including age and #)

Other (specify including age and #)

11. Recruitment of participants (Check all that apply.)

Unpaid classroom volunteer

Paid classroom volunteer

Unpaid nonclassroom volunteer

Paid nonclassroom volunteer

Other (Please specify)

RESOURCES FOR IMPROVED WELLNESS & WELLBEING FOR INDIVIDUALS WITH ULL/D

How will participants be recruited (please attach any flyers, email content, etc.)? Please list all inclusion/exclusion criteria.

Participants will be recruited through e-mail using a contact list provided by Jodie from Destiny's Ride of current program stakeholders from a series of non-profit organizations with therapeutic recreation programs. The invitation to participate is found in Appendix A.

12. Expected study duration and compensation.

Expected Duration (e.g., total hours and length of involvement (days, months) per participant):

Research for this program is expected to be performed for eight weeks. In addition, two online surveys will be used pre-and-post research that will take 15 minutes each to answer, totaling 30 minutes per participant.

Expected participant compensation (Check all that apply.)

No compensation \$\$ compensation

Other (Please specify)

If applicable, please specify \$\$ rate

13. Location of the research (Check all that apply)

On-campus On-Line Off-Campus

Please specify site (e.g., Springfield campus, Southborough, specific off-campus location)

Western New England Campus, Destiny's Ride, Google Forms

Note: If off-campus locations are included, please attach a signed permission from a responsible individual (e.g., business owner, school superintendent, principal) for each location.

14. Will the participants be exposed to more than minimal risk?

Yes No

Please briefly describe any anticipated risks, discomforts, or inconveniences related to participation, and what will be done to minimize these.

Please refer to the risk part of the consent form in Appendix B

15. Describe consent and/or procedure (attach copies of written informed consent form or information sheet and use consent form checklist to ensure that it contains required elements). Who is obtaining consent? Where and when will it be obtained? How will it be obtained from non-English speakers, if relevant? **Attach copies of consent and assent forms.**

Consent forms will be sent to program stakeholders in the recruitment email. Once the participant returns their response and sign consent, the survey link will be provided. The survey responses will be anonymous. A copy of the consent is attached in Appendix B.

16. Confidentiality and anonymity of information obtained (Check all that apply)

Participants' responses will be anonymous. (Data are collected in a way that no one (including the researcher) can identify the individual associated with any particular result or response, e.g., a survey with no names or other identifying information.)

Participants' responses will be confidential. (Records are maintained in a way that ensures only the researchers have access to any information or results linked to a specific individual.)

Other (Please specify)

17. Does the research involve the use of deception?

Yes No

If "Yes" please elaborate in the space below, describing the deception used and providing a justification of the need for deception.

No use of deception

18. Does the research involve debriefing of participants?

Yes No

If "Yes" please provide an explanation in the space below describing how (e.g., spoken, with written statement) and when the participants will be debriefed. If "No" please provide an explanation of why debriefing is not necessary. Provide a copy of the debriefing statement as an attachment, if relevant.

No debriefing required.

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19. Data collection methods: Describe data collection methods to be used (e.g., survey instruments - **copies must be submitted as attachments**), the types of data to be collected (e.g., electronic, hard copy, video), where it will be stored and for how long, who will have access to the data and any security protections that will be put in place.

The responses and consent forms will be stored/ downloaded to a password-protected computer, and stored for six years. Only the student researcher will have access to the data. The researcher will use Google Forms to compile all responses and perform an initial quantitative analyses to guide decisions about what to include in the program research. The survey instruments are attached as Appendix C.

20. In the space below, please provide a thorough description of the research procedure(s), including design, what specific procedures will be used in each phase of the study, etc.

Participants who are current board members of the non-profit organization Destiny's Ride will be invited via email to participate in an anonymous online pre-survey regarding their program's needs to improve program development and a post-survey regarding the deliverables provided and their satisfaction with the overall outcomes. The survey consists of 10 questions that will take about 15 minutes each. The survey will remain open for approximately ten days following the invitation notice. The student researcher will use a "mixed method" pre-and-post survey. The pre-survey will consist of four open-ended, five multiple-choice, and one Likert scale questions. The post-survey will consist of six questions with four Likert scales and two open-ended questions, created as an electronic Google survey document. All responses are anonymous and do not contain identifiers. The researcher will use Google Forms to compile all responses and perform an initial quantitative analyses to guide decisions about what to include in the program research. The student will perform a thematic coding analyses for open ended questions.

21. Are you applying for an exemption? Yes No

NOTE: If "Yes" please submit the Exemption Code # in the space below, citing your specific reason. For a listing of reasons, go to <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html> (Refer to 46.104.)

46.104.d.2.i Exempt research.
Research involving normal education and program development to support stakeholders and program directors.

22. Online Training Requirement

The IRB has a mandatory training requirement prior to protocol approval. Training is conducted through the Collaborative Institutional Training Initiative (CITI) Program. Instructions on how to access this training can be obtained at <https://www1.wne.edu/academic-affairs/institutional-review-board.cfm>. **Please attach a current copy of your certificate to your application submission.**

23. Assurances:

I certify that I have read and followed the the Belmont Principles (<http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>) and the American Psychological Association's* ethical principles concerning research with human participants (<http://www.apa.org/ethics>). I will adhere to the policies and procedures explained therein. Should changes in the procedure or consent form described above (or in related documents) become advisable, I will submit them to the IRB for approval. I understand that the responsibility for the ethical conduct of the study rests with the responsible faculty investigator. I agree to report any participant complaints that may arise to the IRB.

NOTE: It is strongly recommended that all researchers consult the education training materials available on human subjects research protection at: <http://www.hhs.gov/ohrp>.

(*Departments or Colleges/Schools that have established their own Human Subjects Committee may substitute the appropriate professional organization's ethical guidelines for research after approval from the IRB.)

1. Responsible Project Investigator's Signature:	<input type="text"/>	Date <input type="text" value="05/02/2023"/>
2. Investigator's Signature, If Different	Alyssa K. Daniels	Date <input type="text" value="05/02/2023"/>
3. Investigator's Signature, If Different:	<input type="text"/>	Date <input type="text" value="05/02/2023"/>
4. Investigator's Signature, If Different:	<input type="text"/>	Date <input type="text" value="05/02/2023"/>
5. Investigator's Signature, If Different:	<input type="text"/>	Date <input type="text" value="05/02/2023"/>

You may not begin conducting any aspect of the proposed study until such time as you have received written approval for the proposal.

Appendix A: Recruitment Email

Dear Potential Participant,

I am an occupational therapy doctoral student from Western New England University, and I am working on my doctoral experiential capstone project (DEx), which focuses on finding funding and resources for non-profit organizations to increase the quality and participation in therapeutic recreation programs for individuals with upper limb loss absence (ULA) or any other related conditions. Related conditions include hemiplegia, brachial plexus injuries, etc. This project comprises virtual-based research methods that will be fully accessible to access at your convenience at the end of this program. The final resource manual provided by mid- July through the *Unlimbited Wellness* program © 2018 may include funding and grant information, therapeutic riding information, program development tips, and therapeutic recreation equipment, providing diverse prosthetic technologies.

This study has been approved by the Western New England University Institutional Review Board (IRB). All information gathered will be confidential, and no names will be included in the findings to the public. We received your contact information from Jodie O'Connell-Ponkos and want you to participate in our study. You will be required to complete at least the pre-survey regarding program needs for further program development; this will take about 15 minutes to complete. You are encouraged to participate in a post-survey regarding resource satisfaction and project outcomes; this will take about 15 minutes to complete. Please respond within a week with your interest in participating in our program. If interested, please get in touch with alyssa.daniels@wne.edu with your response and signed letter of consent.

Thank you,

Alyssa K. Daniels OT/s



Appendix B: Consent Form

1215 Wilbraham Road

Springfield, MA 01119

Phone: (413)782- 3111



Informed Consent Form

Title of Study: *Unlimbited* Recreation: Access to Prosthetic Technology and Services for Improved Wellness & Wellbeing

You have been invited to participate in a study that has potential benefits for program development for non-profit organizations. You are qualified by being at least 18+ years of age, a board member or stakeholder, and an active participant at Destiny's Ride. Dr. Debra Latour OT, PP-OTD, M.Ed., OTR, and Alyssa K. Daniels, a Doctor of Occupational Therapy student from Western New England University, is conducting this research project. Would you please take the time to review the information below thoroughly before agreeing to participate in this study?

Purpose: *UnLimbited* Recreation is a program to serve non-profit organizations that serve those in the upper limb absence (ULA) population. This program will work with program directors and stakeholders to access therapeutic programs to help promote increased funding and improve the program's overall quality. The occupational therapy student will perform exhaustive research and work with stakeholders from Destiny's Ride to determine appropriate funding support and resources for the program's development. Once the resources have been collected, they will be returned to the program directors. The managed resources will be available to access through the *Unlimbited* Wellness program © 2018 and a printed manual to promote increased accessibility.

This study aims to investigate possible funding and available resources to increase program development for therapeutic recreation programs for individuals with ULA to promote overall quality of life and increase participation in leisure activities.

Procedure: This program will be evaluated using a pre-survey to determine stakeholders' view of the program's needs to promote further development and a post-survey to assess the program stakeholder's overall satisfaction with the resources provided. This doctoral experiential program aims to develop support, funding, and developmental resources for therapeutic recreation programs that serve individuals with ULA. The whole purpose of this program is to create personalized resources and support through the *Unlimbited* Wellness program © 2018 for non-profit organizations and their clients based on their survey responses. The goal is to have increased quality and funding for therapeutic recreation for individuals with ULA.

Potential Risks: Much of this study will be performed virtually. However, it is essential to note that the topics discussed in the manual may be triggering. For example, you may find that reading manual topics can cause mental or physical fatigue. However, you may decline to participate in any portion of the study that you are uncomfortable with and may voice concerns to the investigators at any time.

Benefits of Participation: Therapeutic recreation is a newer and upcoming service for individuals with ULA. Providing current and future programs with more funding resources will significantly benefit the empirical and objective goals and participation in this type of recreational therapy. Even though each individual participating can have various degrees of disabilities, programs can be tailored to best suit the participant's needs to ensure they obtain the most significant benefit from the therapy sessions. Also, providing the public with more knowledge about this type of therapy will increase awareness among people, provide more funding opportunities, and see if it suits as a potential addition to other non-profit organizations.

Confidentiality: Participant scores and results from this study will be stored in a secure, password protected computer system. Researchers of this study will be the only individuals with access to this information. Participant files will only be used for this study and will not be shared with other researchers conducting similar studies. Participants can ask for their files at any time throughout the study process. Participants can pick up their paperwork at any session throughout the 14- weeks. After the study is over, results and forms can be sent in the mail in a sealed envelope. After six years post the *Unlimbited* Recreation program, all results will be permanently terminated for the electronic and paper records.

Right to Refuse or Withdraw: Participants are entitled to refuse or withdraw from this study at any point in time without bias.

For More Information: Participants can contact us with further questions or concerns before or during the study. Subjects have a right to ask questions or report any problems. The head researcher Alyssa K. Daniels can be reached by phone at (203) 537-1865 or by email at alyssa.daniels@wne.edu. The Western New England University Institutional Review Board has reviewed and approved this study.

Contact:

If you have any questions or concerns about the “rights of research subjects”, you may contact Dr. Jessica Carlson, Chair of the Institutional Review Board, at 413-796-2325, jessica.outhouse@wne.edu, or Dr. Minna Levine, College of Pharmacy & Health Sciences, Member of the Institutional Review Board, at minna.levine@wne.edu. This research project has been reviewed and approved by the Western New England University Institutional Review Board.

State of Consent: By signing below, you indicate that you are at least 18-25 years old and an active board member or stakeholder for Destiny's Ride. Your signature indicates that you have

agreed to participate in this program development study as a research subject. You can request a signed and dated copy of this form to keep in your records.

Participant Signature: _____ Date: _____

Print Name: _____

OTD/s signature: _____ Date: _____

Appendix C: Pre- Survey

Unlimited Recreation: Access to Resources for Improved Wellness & Wellbeing for Individuals w/ ULL/D

This doctoral experiential project aims to create a funding and resource manual based on specific needs for non-profit organizations that are working to develop therapeutic recreation programs for individuals with upper limb absence (ULA). This manual will include aspects of funding/ grant information, program improvement interventions, education on technology and devices, and informational newsletters to help to continue to further development of existing therapeutic recreation programs.

What is your profession? (i.e. OT, riding instructor, life coach, etc.)

What is your role within Destiny's Ride?

How long have you been involved with Destiny's Ride?

- **0-6 months**
- **6 months- 1 year**
- **1-2 years**
- **>2 years**

How well do you understand the organization's mission, vision, and values?

- **1 not at all**
- **5 very well**

What would make the greatest difference in helping Destiny's Ride get better at what it does?

- **Increased social media following**
- **Non-riding program options (i.e. yoga, VA, exercise programs, etc.**
- **Fundraiser ideas**
- **Increased community involvement**
- **Addition of a news letter**

In your opinion what resource is most important for me to provide for Destiny's Ride to help continue to promote increased program development?

- **Social media templates**
- **Education and resources for funding/ grants**
- **Development ideas for non- riding programs**
- **Creation of a news letter template**
- **Other**

How do you keep your supporters up to date about your program?

- **Social media**
- **Email**
- **Phone calls/ text**
- **Mail**
- **Website**

Would you be willing to participate in a social media crash course?

- **Yes**
- **No**

What are areas of opportunity for your organization? What could you do better?

Is there anything that you wish more people knew about Destiny's Ride?

Appendix C: Post Survey

Unlimbited Recreation: Student Final Survey

This doctoral experiential project aims to create a funding and resource manual based on specific needs for non-profit organizations that are working to develop therapeutic recreation programs for individuals with upper limb absence (ULA). This manual will include aspects of funding/ grant information, program improvement interventions, education on technology and devices, and informational newsletters to help to continue to further development of existing therapeutic recreation programs.

How satisfied are you with the outcomes of this project?

- **1 not at all**
- **5 Very satisfied**

Do you feel as though your programs resources have increased as a result of the OTD students efforts?

- **1 Not at all**
- **5 Yes I do**

Do you feel that the resources provided are sustainable for future use?

- **1 not at all**

- **5 yes I do**

How was the students collaboration with other members of the program?

- **1 poor**
- **5 very good**

What did the student do well during their time with you and your program?

What can the student improve on for future interprofessional projects?

Appendix D: Letter of Support Single-Handed Solutions. LLC



April 11, 2023

To Whom It May Concern;

As the Owner of Single-Handed Solutions, LLC, I give my permission to WNE OTD students Alyssa Daniels and Amelia Lee to use the *Unlimbited* Wellness program © 2018 as part of their Doctoral Experiential Capstone project.

With Kind Regards;

A handwritten signature in black ink that reads "Debra Latour". The signature is fluid and cursive.

Debra Latour, OT, PP-OTD, M.Ed., OTR

Appendix E: Letter of Support Destiny's Ride

To whom it may concern,

As the Founder and Executive Director of Destiny's Ride Therapeutic Program, Inc, *I give my permission to WNE OTD student Alyssa Daniels to use the Not-for Profit Destiny's Ride Therapeutic Program Inc. as part of their Doctoral Experiential Capstone project.*

With Kind Regards.

Jodie O'Connell-Ponkos

Jodie O'Connell-Ponkos BS, COTA/L

Appendix F: Letter of Support Enhancing Skills for Life



To whom it may concern,

As the Owner of Enhancing Skills for Life, *I give my permission to WNE OTD student Alyssa Daniels to use Enhancing Skills for Life, 501c3, as part of their Doctoral Experiential Capstone project.*

With Kind Regards;

A handwritten signature in black ink that reads 'Shawn Johnson'. The signature is fluid and cursive, with a long horizontal stroke at the end.

Shawn Johnson, OTR

Appendix G: Faculty Mentor CITI Program Certification



Completion Date 27-Mar-2023
Expiration Date 27-Mar-2026
Record ID 55124458

This is to certify that:

Debra Latour

Has completed the following CITI Program course:

Not valid for renewal of certification through CME.

Social & Behavioral Research - Basic/Refresher
(Curriculum Group)
Group 3: Social-Behavioral-Educational Researchers
(Course Learner Group)
1 - Basic Course
(Stage)

Under requirements set by:

Western New England University



101 NE 3rd Avenue, Suite 320
Fort Lauderdale, FL 33301 US
www.citiprogram.org

Verify at www.citiprogram.org/verify/?wabe0c3ab-f79f-4563-9496-c52dd3ed34b9-55124458

Appendix H: Student Researcher CITI Program Certification



Completion Date 03-Jul-2021
Expiration Date 02-Jul-2024
Record ID 43095942

This is to certify that:

Alyssa Daniels

Has completed the following CITI Program course:

Not valid for renewal of certification through CME.

Biomedical Research - Basic/Refresher
(Curriculum Group)
Group 2: Biomedical Researchers
(Course Learner Group)
1 - Basic Course
(Stage)

Under requirements set by:

Western New England University



Verify at www.citiprogram.org/verify/?wf28a0b68-416a-4b0d-b650-1b848cb67704-43095942

Appendix E

Submitted Poster Abstracts

AOTA Call for Papers

Proposal title: Unlimbited Recreation: Access to Services for Improved Wellness & Wellbeing

Type of proposal: general

Session format: poster

Speakers and authors:

- Primary speaker: Alyssa K. Daniels OT/s,
- Contributing author: Debra Ann Latour OTD, Med, OTR/L

Abstract synopsis (250 characters): Unlimbited Recreation created a manual for non-profit directors, focusing on therapeutic recreation for individuals with diverse challenges, including upper limb absence. It offered resources for program development and a core strengthening plan.

Learning objectives:

- Participants will develop an understanding of upper limb absence, including its causes, potential impacts on daily life, and available resources.
- Participants will comprehensively understand grant funding, including the various types of grants available, the application process, etc.
- Participants will be able to recognize the benefits of core strengthening exercises in relation to enhancing horseback riding performance.

Abstract: (2,000)

Upper limb absence could occur congenitally or through acquired conditions, but it was often grouped with lower limb loss despite their distinct differences. Individuals with upper limb absence (ULA) face unique challenges, including depression and financial hardships. Their medical expenses were estimated to be \$150,000 higher than those without limb loss.

The projected increase in people with limb loss by 2050 highlighted the need for greater medical support and inclusive programs. Non-profit organizations strived to create a safe environment with appropriate equipment and resources to engage and involve individuals with diverse challenges, such as the ULA population. Unlimbited Recreation was an example of a program catering to individuals with various challenges, including ULA. A student researcher collaborated with program directors and stakeholders to assess therapeutic programs, identify funding and quality improvement needs, and conduct extensive research. They also worked with stakeholders from Destiny's Ride and Enhancing Skills for Life to secure funding and resources for program development.

Through an extension of the Unlimbited Wellness Program © 2018, this program also provided a core strengthening plan for participating equestrian riders at Destiny's Ride. A core strengthening program for horseback riding is crucial to enhance stability, balance, and control. It helps riders maintain proper posture and body alignment, reducing the risk of injuries and improving overall performance.

RESOURCES FOR IMPROVED WELLNESS & WELLBEING FOR INDIVIDUALS WITH ULL/D

This study explored funding options and available resources to enhance program development for non-profit organizations such as Destiny's Ride and Enhancing Skills for Life. These organizations offered recreational therapy programs for individuals with diverse challenges and ULA to improve their overall quality of life and promote participation in leisure activities. The ultimate goal was to support these organizations in effectively serving the ULA population.

Primary topic category: General & Professional Issues

Secondary topic category: Administration & Management

Additional Information:

- Consideration requests: none of the above
- Level of material: Intermediate level
 - o Rationale (500 words) 137 remaining: The poster aims to showcase the role of non-profit organizations in promoting program development specifically tailored to individuals with upper limb absence. By providing a personalized resource manual, directors and board members can access valuable information to enhance existing programs or create new ones, ensuring equal opportunities and support for all.
- Policies governing accepted proposals: I agree
- References:
 - o Diniz LH, de Mello EC, Ribeiro MF, Lage JB, Bevilacqua Júnior DE, Ferreira AA, et al. Impact of hippotherapy for balance improvement and flexibility in elderly people. *J Bodyw Mov Ther* 2020;24(2):92e7. <https://doi.org/10.1016/j.jbmt.2019.10.002>.
 - o Gazley, B., & Guo, C. (2020). What do we know about nonprofit collaboration? A systematic review of the literature. *Nonprofit Management & Leadership*, 31(2), 211–232. <https://doi.org/10.1002/nml.21433>
 - o Latour, D. (2019). Unlimbited Wellness: Telehealth for adults with an upper-limb difference. *JPO Journal of Prosthetics and Orthotics*, 31(4), 246–256. <https://doi.org/10.1097/jpo.000000000000263>
 - o The University of Utah. (2023). Teaching for the future of occupational therapy (OT) and recreational therapy (RT). U Health. Retrieved April 12, 2023, from <https://health.utah.edu/occupational-recreational-therapies/about>
- Special accommodations:
 - o No
 - o Yes, I can present on a Saturday.
 - o No
 - o Post- conference: yes



CALL FOR PROPOSALS - CONFERENCE 2023

- Proposals must be received via email to info@maot.org by May 31, 2023
- Form must be completed electronically
- Each proposal must include resumes for each presenter
- Provider Agreement/Disclosure/Attestation form must be signed by each presenter

Title of Presentation or Poster (Limit 8 words or less):

Unlimited Recreation: Access to Prosthetic Technology and Services for Improved Well

Presenter #1

Name, Credentials, Job Title, Affiliation or Organization: (This presenter will be the primary contact person for the MAOT Conference Committee)

Alyssa K. Daniels OT/s Western New England University

Phone: (203)537-1865

Email: alyssa.daniels@wne.edu

Presenter #2

Name, Credentials, Job Title, Affiliation or Organization:

Dr. Debra Latour OT, PP-OTD, M.Ed., OTR

Phone: (413)519-0636

Email: debra.latour@wne.edu

Presenter #3

Name, Credentials, Job Title, Affiliation or Organization:

Phone:

Email:

(Add additional presenters as needed by including an additional a document with Presenter info and biographical sketch)

Presentation Abstract (75 words or less to be published in the brochure):

Unlimbited Recreation aimed to create a personalized resource manual for directors and board members of non-profit organizations offering therapeutic recreation programs for individuals with diverse challenges including upper limb absence (ULA). This program provided resources to promote further program development for new and developing non-profit organizations. Through an extension of the Unlimbited Wellness Program © 2018, this program also provided a core strengthening plan for participating equestrian riders at Destiny's Ride.

Learning Objectives (3):

By the end of this presentation/poster, participants will be able to:

1. Participants will develop an understanding of upper limb absence, including its causes, potential impacts on daily life, and available resources.
2. Participants will gain a comprehensive understanding of grant funding, including the various types of grants available, the application process, and best practices for securing grant funding.
3. Participants will be able to recognize the benefits of core strengthening exercises in relation to horseback riding and acquire a basic knowledge of core strengthening exercises that can enhance their riding performance.

Proposal (250-500 words for presentation, 150-250 words for poster):

Upper limb absence could occur congenitally or through acquired conditions, but it was often grouped together with lower limb loss despite their distinct differences. Individuals with upper limb absence (ULA) faced unique challenges, including depression and financial hardships. Their medical expenses were estimated to be \$150,000 higher than those without limb loss.

The projected increase in the number of people with limb loss by 2050 highlighted the need for greater medical support and inclusive programs. Non-profit organizations strived to create a safe environment with appropriate equipment and resources to engage and involve the ULA population. Unlimbited Recreation served as an example of such a program, catering to individuals with ULA. A student researcher collaborated with program directors and stakeholders to assess therapeutic programs, identify funding and quality improvement needs, and conducted extensive research. They also worked with stakeholders from Destiny's Ride to secure funding and resources for program development. Managed resources were provided through Unlimbited Wellness and a printed manual to enhance accessibility for program directors.

This study aimed to explore funding options and available resources to enhance program development for non-profit organizations such as Destiny's Ride and Enhancing Skills for Life. These organizations offered recreational therapy programs for individuals with ULA, seeking to improve their overall quality of life and promote participation in leisure activities. The ultimate goal was to support these organizations in effectively serving the ULA population.

References (3-5 references within the past 5 years using APA-7th edition):

1. ATRA. (n.d.) About recreational therapy. ATRA.com, Retrieved April 12, 2023, from <https://www.atra-online.com/page/AboutRecTherapy>
2. Diniz LH, de Mello EC, Ribeiro MF, Lage JB, Bevilacqua Júnior DE, Ferreira AA, et al. Impact of hippotherapy for balance improvement and flexibility in elderly people. J Bodyw Mov Ther 2020;24(2):92e7. <https://doi.org/10.1016/j.jbmt.2019.10.002>
3. Gazley, B., & Guo, C. (2020). What do we know about nonprofit collaboration? A systematic review of the literature. Nonprofit Management & Leadership, 31(2), 211 – 232. <https://doi.org/10.1002/nml.21433>
4. Latour, D. (2019). Unlimbited Wellness: Telehealth for adults with an upper-limb difference. JPO Journal of Prosthetics and Orthotics, 31(4), 246 – 256. <https://doi.org/10.1097/jpo.0000000000000263>
5. The University of Utah. (2023). Teaching for the future of occupational therapy (OT) and recreational therapy (RT). U Health. Retrieved April 12, 2023, from <https://health.utah.edu/occupational-recreational-therapies/about>

If you are promoting a product within your presentation or poster, please check here:

Educational Level (select one): Refer to *Tip Sheet* for descriptions of each level.

- Student
- Introductory
- Intermediate
- Advanced

Preferred Length (select one):

- Full Day
- 1.5 hour
- 1 Hour
- 30 Minutes (first-time presenters & students only)
- Poster Presentation

Content Area:

- | | | |
|---|---|--|
| <input checked="" type="checkbox"/> Administration/
Leadership | <input type="checkbox"/> Home Health | <input type="checkbox"/> Professional
Development |
| <input type="checkbox"/> Acute Care/Hospital
Clinical Practice | <input type="checkbox"/> Justice/Equity/
Diversity/Inclusion
(JEDI) | <input type="checkbox"/> Research |
| <input type="checkbox"/> Aquatics | <input type="checkbox"/> Mental Health | <input type="checkbox"/> Sensory
Integration/Sensory
Processing |
| <input type="checkbox"/> Assistive Technology | <input type="checkbox"/> Neurology | <input type="checkbox"/> Sports |
| <input type="checkbox"/> Cardiopulmonary
Care | <input type="checkbox"/> Oncology | <input type="checkbox"/> Women's Health |
| <input type="checkbox"/> Developmental
Disabilities | <input type="checkbox"/> OT/OTA Education | <input type="checkbox"/> Work
Practice/Industrial
Rehabilitation |
| <input type="checkbox"/> Emerging Practice | <input type="checkbox"/> Orthopedics | <input type="checkbox"/> Wound Care |
| <input type="checkbox"/> Ethics | <input type="checkbox"/> Pain Management | <input checked="" type="checkbox"/> Other |
| <input type="checkbox"/> Gerontology | <input type="checkbox"/> Pediatrics/School-
Based Practice | |
| <input type="checkbox"/> Hand Rehabilitation | <input type="checkbox"/> Physical Disabilities | |
| | <input checked="" type="checkbox"/> Prevention/Wellness | |

Biographical Sketch (200 words or less for each presenter for introduction at the conference):

Presenter #1

Alyssa is currently in her third year of graduate studies at Western New England University, Alyssa is pursuing a Doctorate in Occupational Therapy (OTD) with a strong focus on working with the pediatric population and individuals with upper limb absence (ULA). She is also committed to expanding her knowledge in therapeutic recreation and advocating for these specific populations.

Alyssa's journey in pediatric care began during her high school years, where she found fulfillment in providing support for individuals with special needs. Her

Presenter #2

Debra Latour, OTD, MEd, OTR/L is the Doctoral Capstone Coordinator and Assistant Professor of Occupational Therapy at Western New England University. Areas of interest are prosthetic rehabilitation, inter-professional collaboration, and program development. She received the COPHS Excellence in Research Award (2019), COPHS Professor of the Year Award (2020), and the MAOT Catherine Trombly Award (2022). Dr. Latour is owner/consultant of Single-Handed Solutions, LLC. She graduated from Tufts University/BSOT (BS, 1978), Springfield College (MEd, 2006) and A.T. Still University (OTD, 2018). She is an active member of Amputee Coalition,

Presenter #3



(Add additional presenters as needed by including an additional a document with Presenter info and biographical sketch)

Please include a copy of recent resume for each presenter and email completed proposal and resumes to info@maot.org by May 31, 2023.

**Thank you!
-MAOT Conference Committee**

Appendix F

Learning Objectives

WNE OTD Objective #1: *Collaborate with various professionals as part of an interprofessional team to advocate the role of occupational therapy in a nontraditional setting.*

WNE OTD Objective #2: *Document a needs assessment for a particular population and use said assessment as the foundation for planning a successful Doctoral Experiential Capstone Project. Additional evidence will include feedback from consumers that indicates the impact of the project on the population they represent.*

WNE OTD Objective #3: *Demonstrate proficiency and professionalism with the use of personal computers, learning platforms, zoom meetings, etc. to fully document and implement Doctoral Experiential Project for WNE as well as for members of the population served.*

WNE OTD Objective #4: *Recognize and be able to describe the diverse systems of service delivery that are most cost-effective and considerate for health, social, and educational settings, both traditional and nontraditional. Through both clinical and reflective writing, be able to articulate a sensitivity to cultural, linguistic, and other diversities and describe solutions for care disparities.*

WNE OTD Objective #5: *Demonstrate the ability to work with others to identify meaningful objectives, organize, manage, and motivate people and resources, communicate effectively, and oversee action to accomplish stated program or service goals*

WNE OTD Objective #6: *Demonstrate the ability to implement in existing programs, and plan for in developing programs, an occupational therapy process that is occupation-based, client-centered, culturally sensitive, and ethically appropriate.*

WNE OTD Objective # 7: *Document an experiential and scholarly project that reflects the literature in restorative justice/community re-entry, and use responsive, ethical methods. The scholarly process and results should be made accessible to the college and the community, especially to the population served by the project. A report of the project, presented in a professional format that others can replicate or build upon, will be evidence of accomplishment.*

WNE OTD Objective # 8: *Through both clinical and reflective writing, be able to articulate a clear awareness of my own personal and professional strengths and boundaries and identify supports and strategies for goal achievement.*

Student Objective # 9: **The student will learn about and support a developing non-profit organization that offers therapeutic recreation programs for individuals with ULA.**

Student Objective #10: **The student educates, empowers, and engages clients and the community through educational resources that provide information on ULA via telehealth and group support.**

Student Objective #11: **The student will provide accessible education and resources to improve overall quality of life for clients and educate community members via telehealth materials available online.**

Student Objective # 12: The student will research and review accessible resources for clients to provide essential information regarding equine therapy, funding, and its benefits for members of the ULA community.