

Enhancing Occupation-Based Educational Support for Families of Children with Congenital Hand and Upper Limb Differences (CHULD)



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Abstract

Families of children with congenital hand and upper limb differences (CHULD) often experience high levels of stress, uncertainty, and limited access to occupation-based education to support their child's development (Thornton et al., 2021; Mazibuko et al., 2022; Clelland et al., 2024; Rodrigues et al. 2022). This capstone project developed and implemented an educational resource initiative aimed at increasing caregiver knowledge, promoting empowerment, and improve access to occupation-based strategies. Findings demonstrate improved caregiver confidence, understanding of adaptive strategies, and perceived ability to support their child's occupational participation. This project aligns with the profession's movement toward family-centered, occupation-based, and population health approaches.

Problem Statement

The scarcity of occupation-based educational support for families of children with CHULD results in parental distress, diminished empowerment, and decreased or delayed guidance for adaptations to support the child (Franzblau et al., 2015; Kelley et al., 2016; Lian et al., 2024; Lage et al., 2024).

Purpose Statement

This Education-type capstone project aims to enhance occupation-based educational support for families of children with CHULD, with an aim to reduce parental distress and foster empowerment.

Capstone Overview

- **Setting:** Scottish Rite for Children HDI Hand Camp & Scottish Rite for Children Hospital, Dallas, TX
- **Population:** Families of children with CHULD
- **Intervention:** Development of occupation-based educational instructional design plan, educational materials, and caregiver resources
- **Design:** Pre/post survey analysis + Instructional design plan implementation + Evidence-based educational resource development with national dissemination
- **Framework:** Evidence-based instructional design guided the development of occupation-based, experiential learning activities and educational resources, including:
 - Backwards Course Design
 - Experiential Learning Theory
 - Constructivist Learning Theory
- **Capstone Experience:** Observing multiple perspectives of patient and caregiver education within Scottish Rite Hospital, including clinic, physician, surgical, and interdisciplinary settings to gather insight into the variability of educational delivery methods, caregiver learning needs, accessibility barriers, and the importance of occupation-based, family-centered education
 - Collaboration with American Society of Hand Therapists (ASHT), demonstrating servant leadership through the development and organization of evidence-based educational resources designed to improve accessibility for hand therapists and the families they serve

Key Outcomes & Results

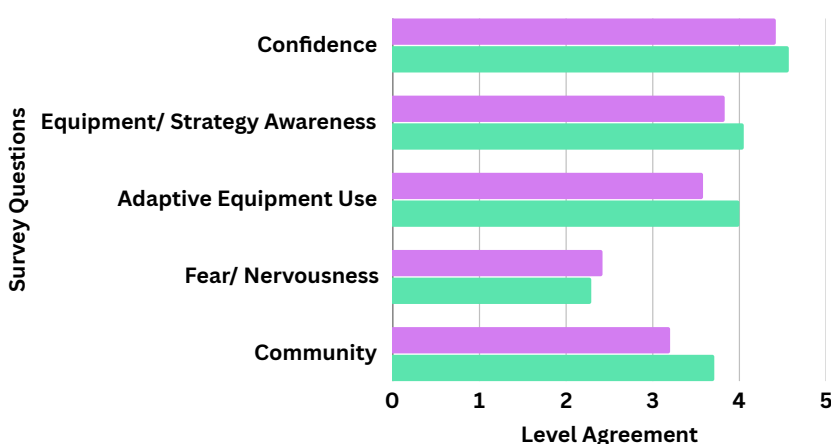
Pre- and post-intervention survey data demonstrated measurable improvements across all domains:

Quantitative Results:

- Increased caregiver confidence (4.4 → 4.6)
 - Improved adaptive equipment use (3.6 → 4.0)
 - Increased awareness of strategies and tools (3.8 → 4.1)
 - Enhanced sense of community and support (3.2 → 3.7)
 - Decreased fear and nervousness (2.4 → 2.2)
- (see **Figure 1**)

Figure 1

Quantitative Survey Results



Note: Survey questions were rates on a Likert Scale including 1= Strongly Disagree, 2= Disagree, 3= Neutral, 4=Agree, 5= Strongly Agree

Pre-Activities Post-Activities

Qualitative Results:

- **Desire for Connection & Community:** Peer support among families was highly valued



“Having her meet other kids who have differences like her.”
“Just being around more similar kids!”
“Having a community to see like people and seeing that confidence grow!”

- **Strengths-Based Reframing:** Caregivers shifted perspectives toward child abilities rather than limitations



“She is not limited at all by her limb difference.”
“It’s not about the exact steps... it’s about getting to the end result.”
“He just has his normal and we figure out his tools and onward!”

- **Encouraging Independence:** Increased willingness to allow children to attempt tasks independently



“It was a good reminder to let my kiddo try before I intervene.”
“Letting her independence be a positive attribute.”

- **Value of Experiential Learning:** Hands-on, camp-based learning was described as impactful and “eye-opening”



“It’s a very eye-opening camp...”
“I wish I could have attended sooner.”
“My understanding has improved.”

Implications for OT

Consistent with the vision of occupational therapy as an accessible, evidence-based, and globally connected profession, the following implications are identified:

1. **Education:** Embedding occupation-based, family-centered education into routine pediatric care supports holistic, participation-focused outcomes and reflects best practices in client-centered care.
2. **Program Development:** Expansion of community-based and experiential learning programs (camp models) can improve access to services and address gaps in traditional service delivery.
3. **Leadership:** Occupational therapists are positioned to lead the development and dissemination of educational resources while advancing caregiver education.
4. **Advocacy:** Needed to support reimbursement structures and institutional policies that recognize caregiver education as a skilled and necessary component of occupational therapy services.

Limitations

- Small sample size limits generalizability
- Short-term data collection restricts understanding of long-term outcomes
- Reliance on self-reported data introduces potential response bias
- Time constraints impacted depth and breadth of implementation
- Likert-scale measures may not fully capture affective learning; qualitative methods are recommended for future research

Recommendations & Next Steps

- Expand occupation-based educational programming into additional pediatric specialty care settings
- Incorporate experiential and community-based learning models into routine OT practice
- Utilize mixed-methods evaluation (interviews, focus groups) to better capture caregiver experiences
- Continue national dissemination through professional organizations and digital platforms

Clinical Bottom Line

The combination of the capstone experience and project enhanced the development of occupation-based, experiential, and family-centered educational interventions. These interventions were effective in improving caregiver confidence, reducing distress, and enhancing support for child participation in meaningful activities. Integrating these approaches into occupational therapy practice, programs, and policy has the potential to significantly improve outcomes for children with CHULD and their families while advancing the profession’s role in holistic, evidence-based care.

References



Oral Defense

