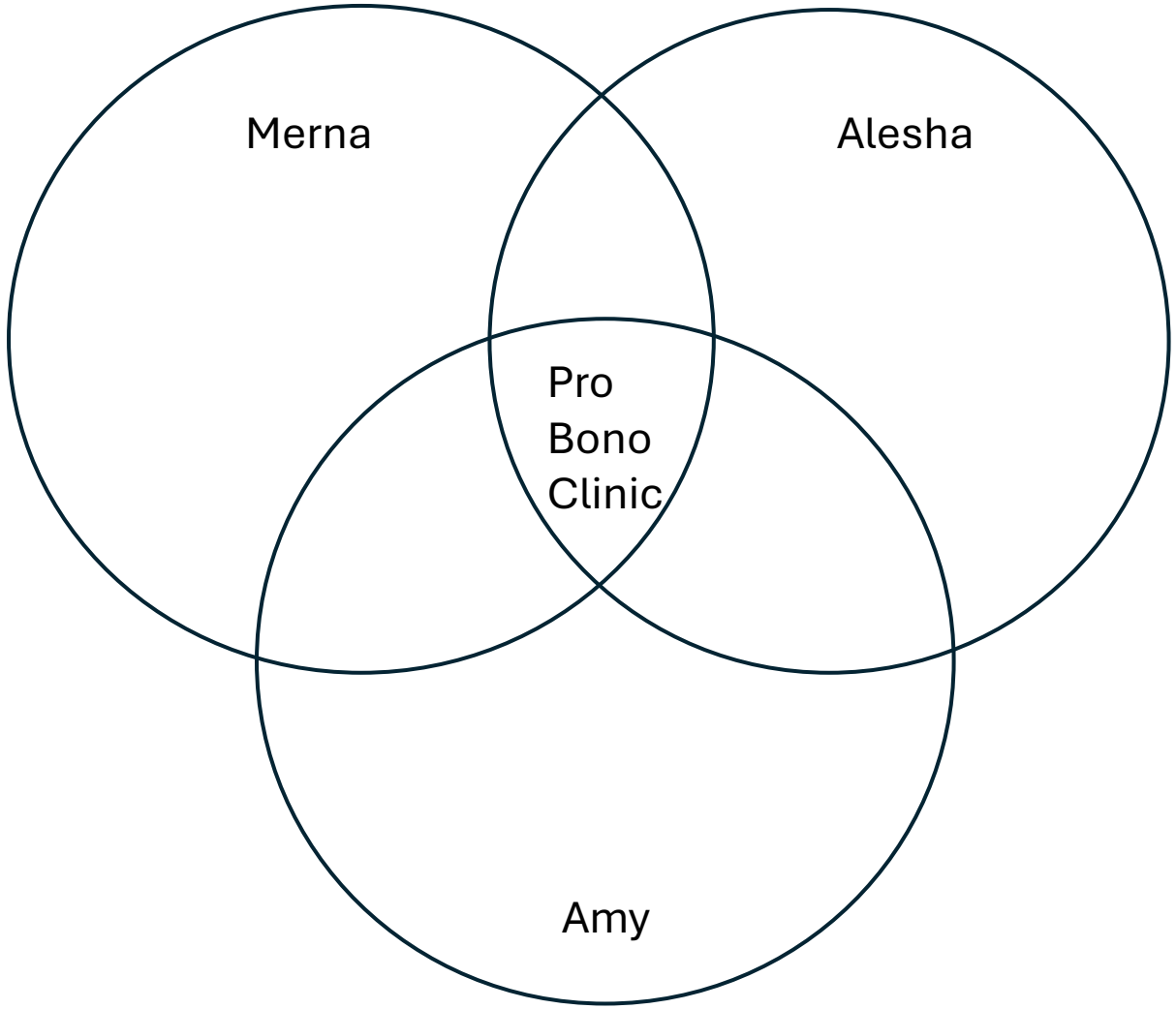
Pro Bono Clinical Experience for Parents with Disabilities

OTAC 2025

Development of the Pro Bono Clinic for Delivery of Occupational Therapy Services



About Alesha

- Nolan was born in March of 2019, at this time I could not find a lot of resources and supports for parents with disabilities.
- In 2020, during COVID, I started sharing adaptive parenting techniques on YouTube in hopes of getting other parents to contribute content and making a safe space for parents with disabilities.
- In 2021, I applied to a contest from Aerie about how I was making change in the community and how I helped a quadriplegic mother put her twins to bed for the first time. Out of 600 applicants, our idea was selected as the top 20 people to get funded. At that time, we were able to start the non-profit Adaptive Parent Project.

About Merna

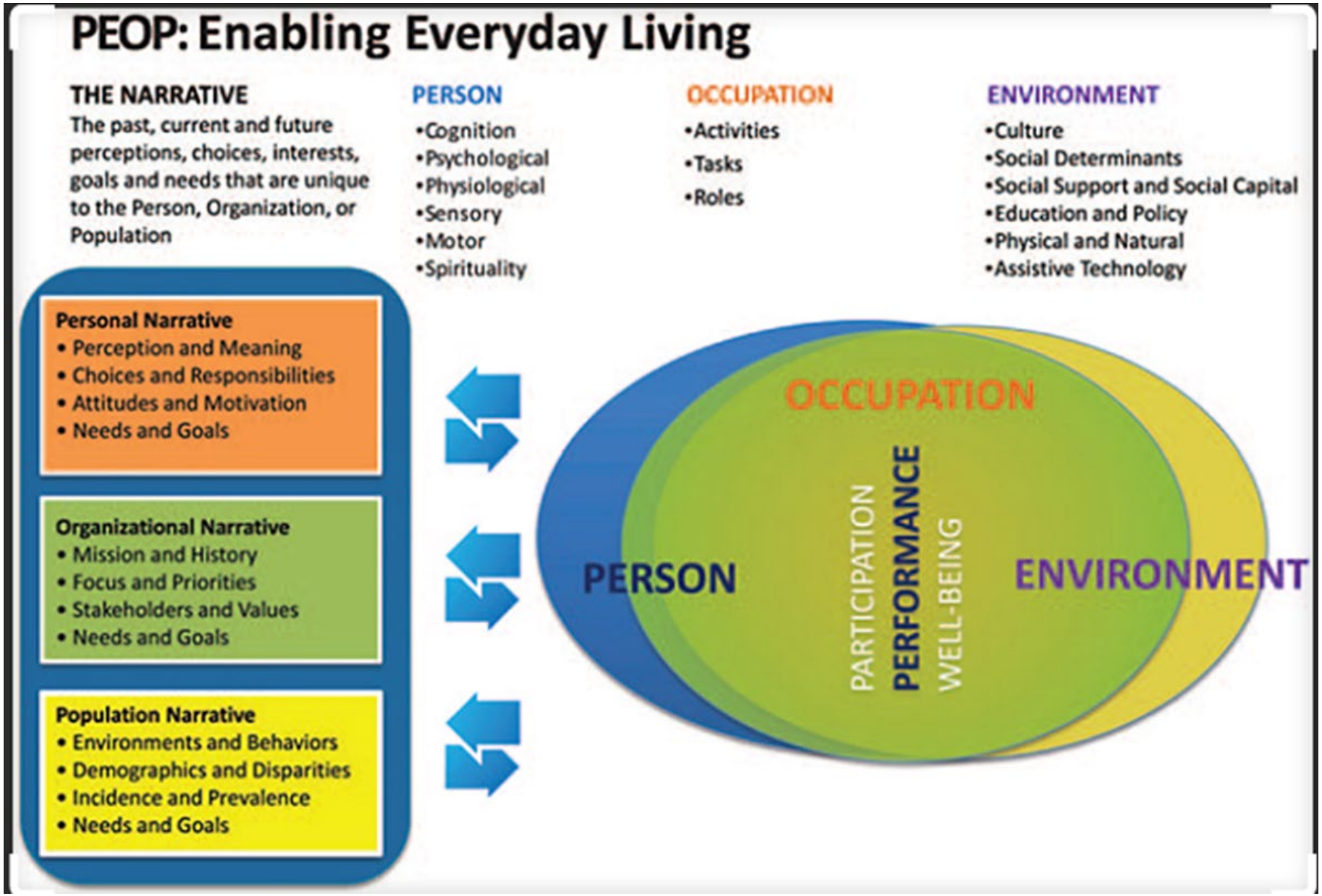
- The idea of the capstone project came from personal experiences when attending church liturgies and observing lack of accessibility for individuals with physical disabilities.
- Further literature review identified a gap in services for parents with disabilities and the potential for occupational therapists to collaborate with parents with disabilities.
- A research OTD capstone project on parenting with a disability was completed with Dr. Amy Lyons-Brown, and I was fortunate to connect with Alesha Thomas as a mentor through a student from a previous cohort.

About Amy

- History of working as an OT in medical and home and community settings with adults.
- Currently working at the University of St. Augustine for Health Sciences in San Marcos, CA, as a Doctoral Capstone Coordinator.
- The collaboration of working with Merna as an OTD student and Alesha as a mentor for a doctoral capstone project on parenting with a disability led to the development of the Transdisciplinary Parenting Collaborative.
- The service delivery is through a telehealth pro bono model utilizing the Pro Bono Clinic at the University of St Augustine for Health Sciences.

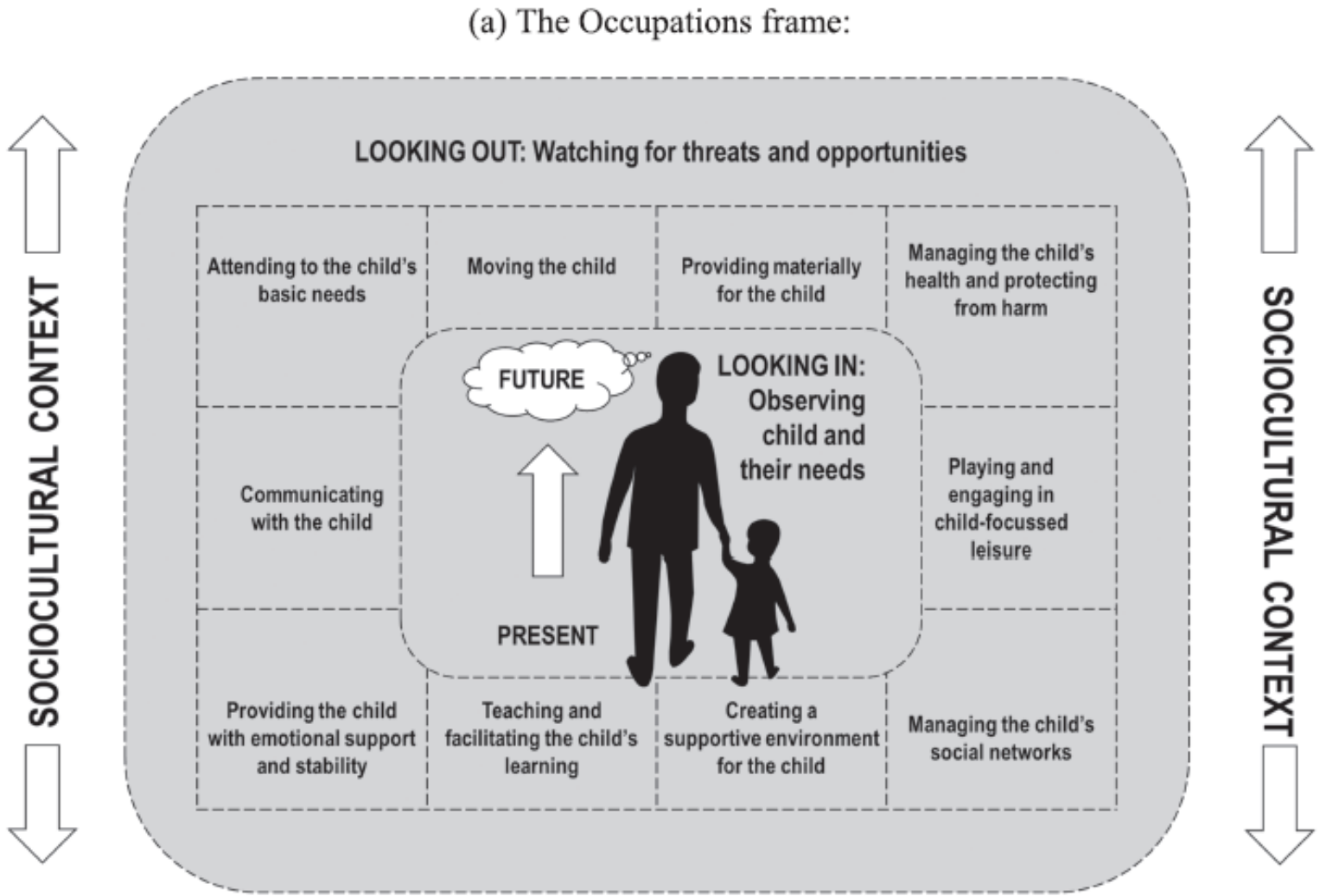
Theoretical Models related to Occupational Therapy and Parents with Disabilities

Person-Environment-Occupation-Performance (PEOP) Model



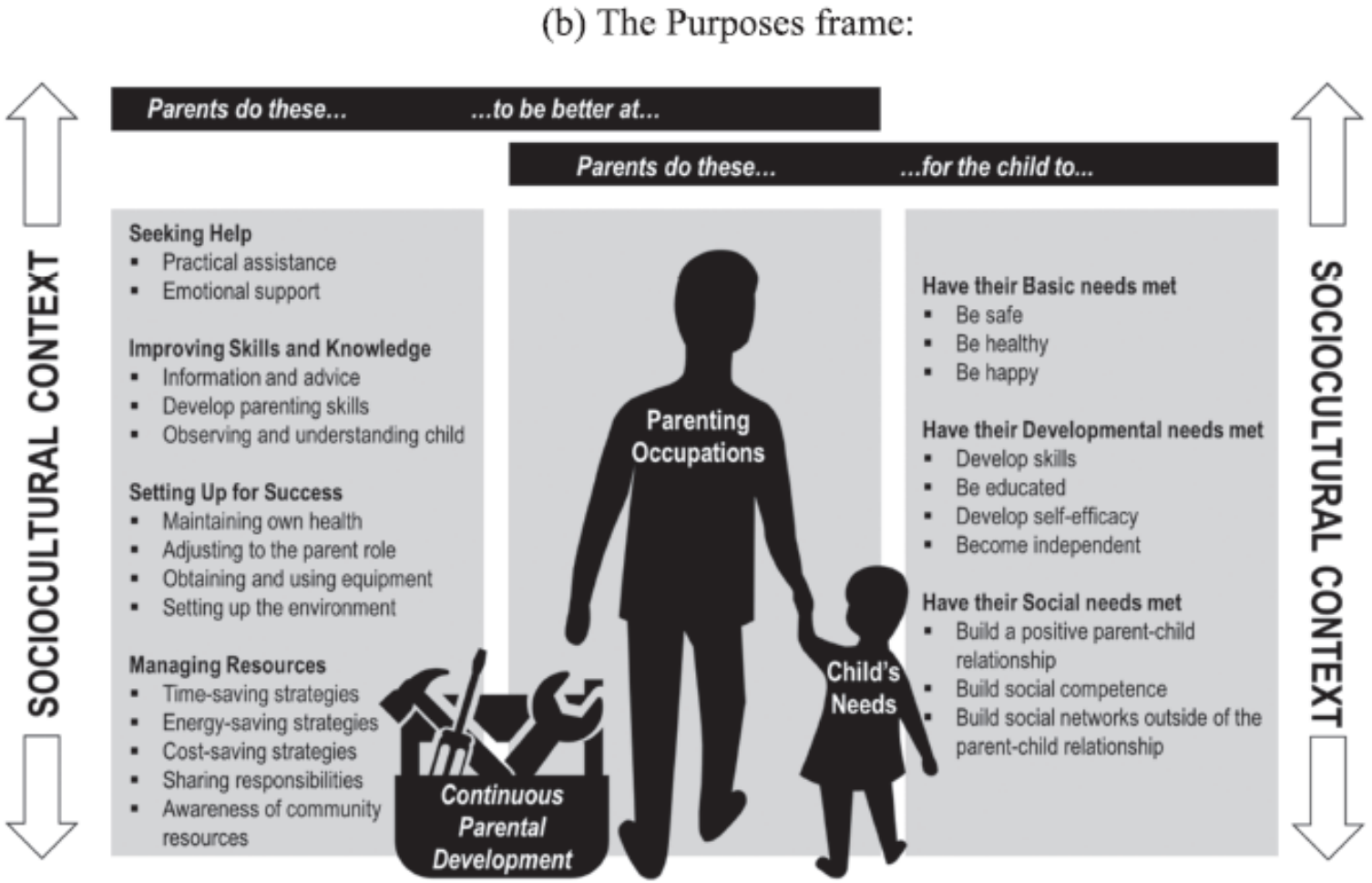
(Baum, Christiansen, & Bass-Haugen, 2015)

Parenting Occupations and Purposes (POP) Framework



(Lim, Honey, & McGrath, 2022)

Parenting Occupations and Purposes (POP) Framework



(Lim, Honey, & McGrath, 2022)

Population Overview

- There are 65.9 million parents in the U.S and 4.4 million parents have disabilities (Sonik et al., 2018).

- Nearly 3.3 million Americans in United States are currently wheelchair users, primarily due to mobility impairment (Nie et. al., 2024).

Literature Review

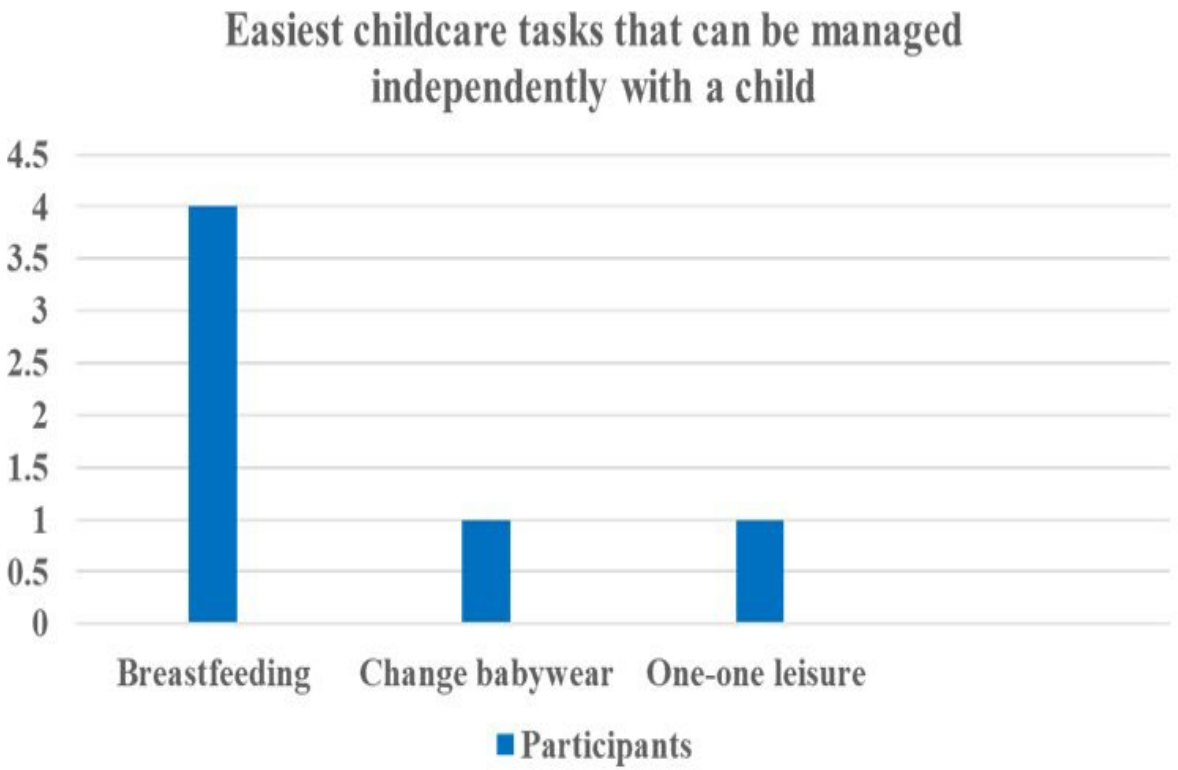
- **There is a lack of knowledge, support, involvement and programs in "doing" parenting in occupational therapy literature for parents with disabilities (Lim et al. 2022).**

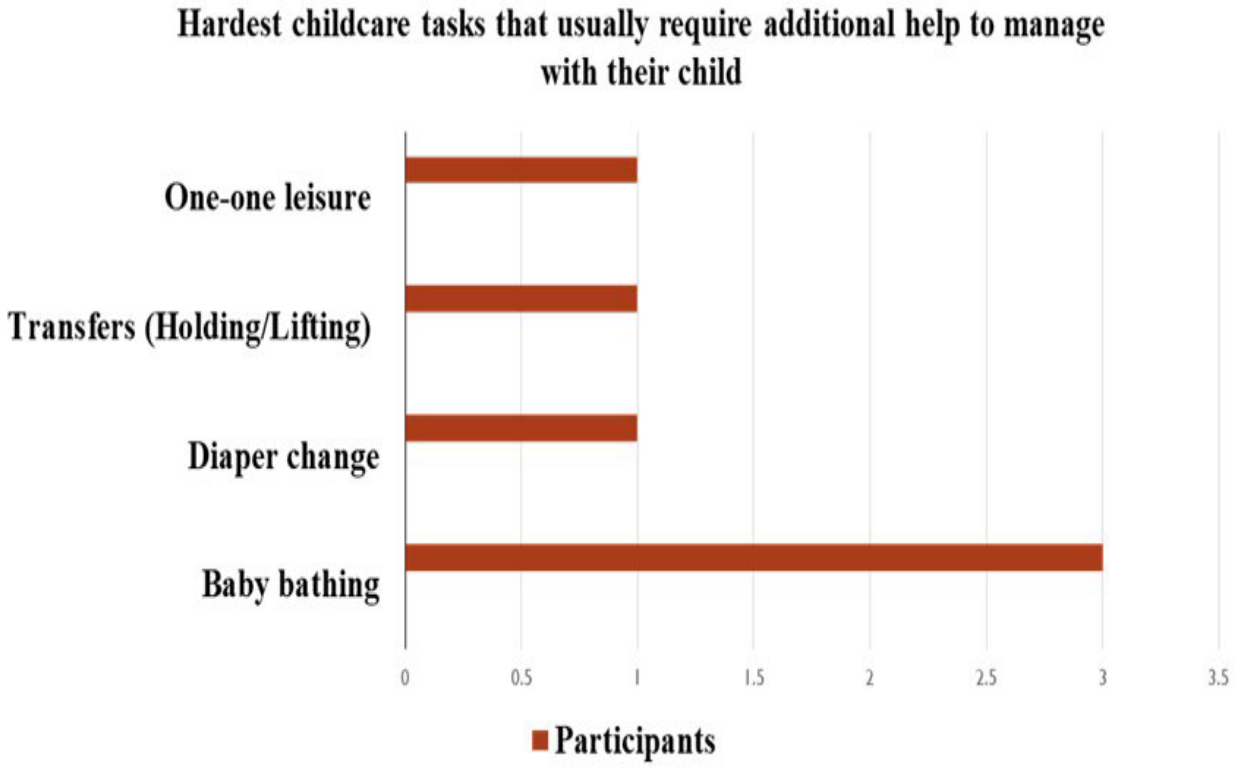
Physical and emotional challenges for parents with physical disabilities can be due to lack of adaptations, decreased self regulation, limited aids, and barriers in accessibility in the natural environment that tend to limit their participation in childcare tasks (Wint et al, 2016).

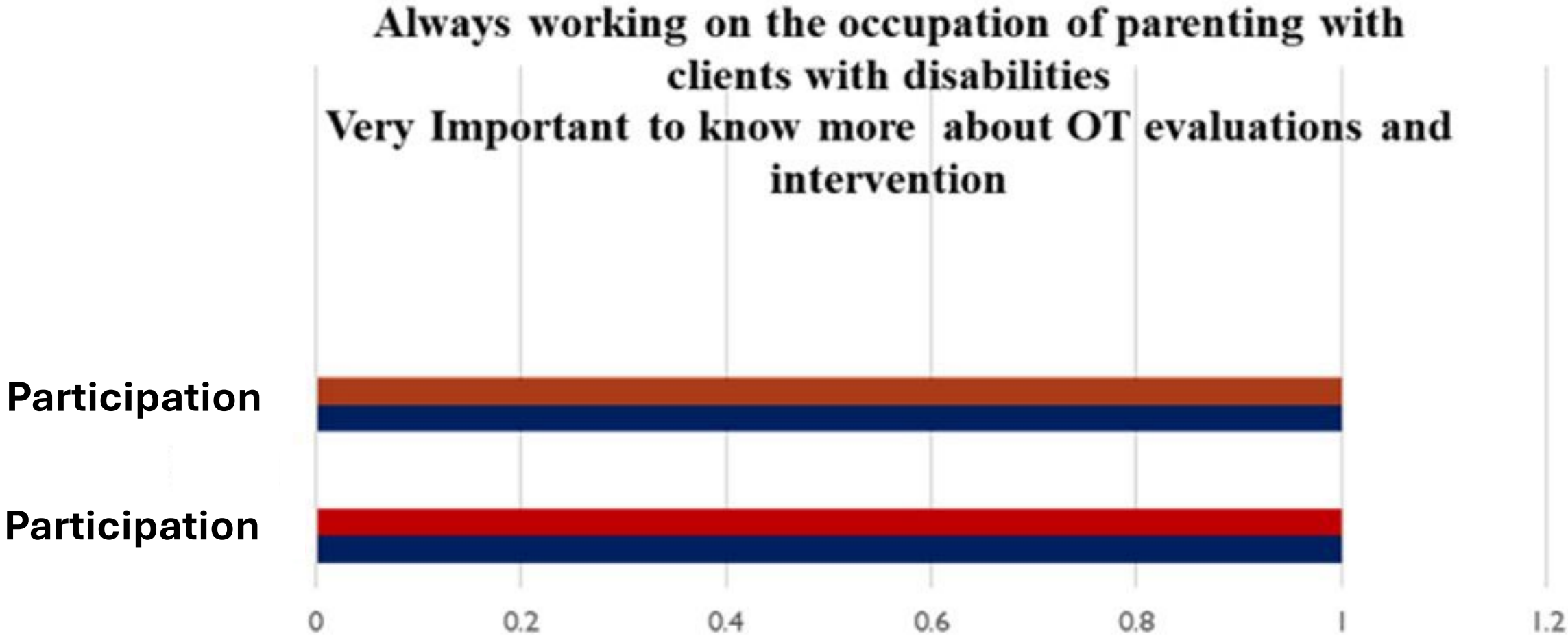
Methodology

- Research Question:
- Mixed Methods Design
- Participants: 6 Parents; 2 OTPs
- Surveys
- Semi-Structured Interviews

Charts


Easiest childcare tasks that can be managed independently with a child
4.5
4
3.5
3
2.5
2
1.5
1
0.5
0
Breastfeeding
Change babywear
One-one leisure
Participants


Hardest childcare tasks that usually require additional help to manage with their child
One-one leisure
Transfers (Holding/Lifting)
Diaper change
Baby bathing
0
0.5
1
1.5
2
2.5
3
3.5
Participants


Always working on the occupation of parenting with clients with disabilities
Very Important to know more about OT evaluations and intervention
Participation
Participation
0
0.2
0.4
0.6
0.8
1
1.2

OT Interventions focused on home modification for parents with disabilities is important

Agree Stronly Agree

Approaches Type mostly used for parents with disabilities from occupational therapists

Create Modify

Findings of 8 Themes

- Access to community
- Challenges and adaptive strategies in home childcare tasks
- Multicomponent adverse challenges in pregnancy, labor and breastfeeding
- Social stigma and environmental barriers
- Home designs with adaptive parenting strategies
- Recommendations to healthcare providers
- Stress management
- The significance of parenting through prenatal programs

Results- Qualitative
Participants: Semi-structured Interview

Themes	Subthemes	Quotes
Recommendation to Healthcare providers	**Assumptions:**	**“ I can't tell you where the safest spot is to put an epidural without hitting my spine. So, I'm not even going to risk it. If I had to go to the emergency C-section, I couldn't get the Spinal Tap either. So, I had to be put out if that happened."**
	See person first:	**"Providers often see the disability first, whereas you need to see the person first and the disability as part of that person. And I think looking at what they can do.”**

Results- Qualitative
Participants: Semi-structured Interview

Themes	Subthemes	Quotes
Social Stigma	Normalizing parenting with a disability	"I don't want everyone staring at me. And who doesn't have a disability?"
	Normalizing Strategies for parents with disabilities	"Like co-sleeping is totally ok and it's normalizing a lot of culture. I'm half Asian and I grew up with that culture like that's normal."

Results- Qualitative
Participants: Semi-structured Interview

Themes	Subthemes	Quotes
In Home Childcare Tasks	Enablers to parenting tasks	"I think dressing is probably the easiest because they actually do help with that. I let them choose, and then they help dress themself at this point."
	Barriers to parenting tasks	“Changing diapers is not fun because they run away and avoid me when they have a poop diaper and they will fight me and I've had to sit there holding them as hard as they can, struggling, pinning them down with my legs at the same time.”

Results

Necessity of improving occupational therapists' knowledge and implementation of adaptive parenting strategies

Parenting with a disability is challenging due to physical factors, emotional factors, environmental barriers and lack of accessibility to services and resources.

The Experience of Using a Pro Bono Clinic to Provide OT Services

Service Delivery Model

Transdisciplinary Care

- *Pro Bono Publico* or “for the public good”

- Being, involving, or doing professional and especially legal work donated especially for the public good

(Merrian-Webster, n.d.)

Strategic direction 4: Improving workforce distribution for equitable access

4 Workforce Distribution & Access

Improving workforce distribution for equitable access in underdeserved areas

Even within nations, inequities exist in the distribution of occupational therapists and population access to occupational therapy services. Inequities in access are commonly defined by factors such as geographic region, urban /rural / remote location, and sector, service, or practice area. With strengthened workforce data and supply shortage determinations, these inequitable distributions within nations can be identified and addressed. Actions may include enhancing recruitment or retention packages, building professional development programmes for those working in underserved areas, or using innovative service delivery models or workforce strengthening approaches that extend the outreach of the occupational therapy workforce to vulnerable populations.

(World Federation of Occupational Therapists, n.d.)

AOTA Vision 2030

(American Occupational Therapy Association, n.d.)

With new leadership in place and a deeply renewed sense of purpose, your AOTA is more focused than ever on continuing its 100-plus-year legacy leading the profession through transformational times with the launch of its new strategic planning initiative: **Vision 2030**.

Vision Statement: Enriching life for ALL individuals and society through meaningful engagement in everyday activities.

Foundational Pillars

Inclusive and Equitable Professional Community	Evidence-Based, Client-Centered, and Innovative Practice	Universally Recognized with Valued Excellence	Occupational Justice and Advocacy
Creates a supportive environment fostering belonging, collaboration, networking, and continuous learning for all professionals to enhance growth and development.	Delivers high-quality and skilled care using latest research, focusing on individual client needs and goals while encouraging innovative approaches to enhance treatment outcomes.	Establishes occupational therapy's importance across various settings, demonstrating its unique value in improving individuals' quality of life and functional abilities.	Promotes education, advocacy, accessibility, and the right for ALL to engage in meaningful occupations through collaboration with consumers, other professionals, and policymakers.

Core Value 4: Justice

- Justice indicates that occupational therapy personnel provide occupational therapy services for all persons in need of these services and maintain a goal-directed and objective relationship with recipients of service.
- Justice is the pursuit of a state in which diverse communities are inclusive and are organized and structured so that all members can function, flourish, and live a satisfactory life regardless of age, gender identity, sexual orientation, race, religion, origin, socioeconomic status, degree of ability, or any other status or attributes.

Principle 4: Justice

- Occupational therapy personnel shall promote equity, inclusion, and objectivity in the provision of occupational therapy services.
- For example, occupational therapy personnel work to create and uphold a society in which all persons have equitable opportunity for full inclusion in meaningful occupational engagement as an essential component of their lives.

(American Occupational Therapy Association, 2020b)

How do clients qualify to participate in this clinic?

UNIVERSITY OF ST. AUGUSTINE
FOR HEALTH SCIENCES

Pro Bono Clinical Experience Eligibility

The University of St. Augustine provides Pro Bono Clinical services as part of our efforts to give back to the community.

Participation in a Pro Bono Clinical Experience is based on the eligibility requirements set forth below. *

By signing below, you are certifying that the information you are providing regarding eligibility including insurance status is true and complete to the best of your knowledge. It also acknowledges that you are responsible to inform the supervising therapist at your facility if there is any change in your eligibility status.

Eligibility (please choose one):

- ☐ No health insurance
- ☐ Health insurance does not cover therapy services
- ☐ Health insurance coverage has been met and no longer covers therapy services
- ☐ Health insurance limitations impact the frequency of therapy services beneficial or necessary to address the condition being treated in therapy (example: needing a program that occurs multiple times a week or for longer sessions than available elsewhere, distance barriers)
- ☐ Health insurance limitations impact the type of therapy services beneficial or necessary to address the condition being treated in therapy (example: needing individual therapy but only eligible for group therapy, distance barriers)
- ☐ Medicare as health insurance but have met allowed visits
- ☐ Medicaid as health insurance and therapy not covered or met allowed visits

How do clients qualify to participate in this clinic?

UNIVERSITY OF ST. AUGUSTINE
FOR HEALTH SCIENCES

Informed Consent and Release Agreement
Pro Bono Clinic Activity

The University of St. Augustine for Health Sciences ("USAHS") provides health science services to adults and children through its pro bono clinics. All services are provided by USAHS students under the direct supervision/guidance of professionals who are licensed to practice in his or her field. Additionally, students may be assigned to watch evaluation/therapy sessions in the clinic or via a telehealth appointment. Evaluation and treatment sessions may be video recorded and viewed by the student and clinical educator as part of routine service delivery. By signing this Informed Consent and Release Agreement ("Agreement"), I consent to receive services in the USAHS probono clinic ("Activity"). I know it is important to read and fill out this form with care and ask a USAHS faculty member if I have any questions. If I have any questions regarding my Activity, I may contact:

University Contact Information:

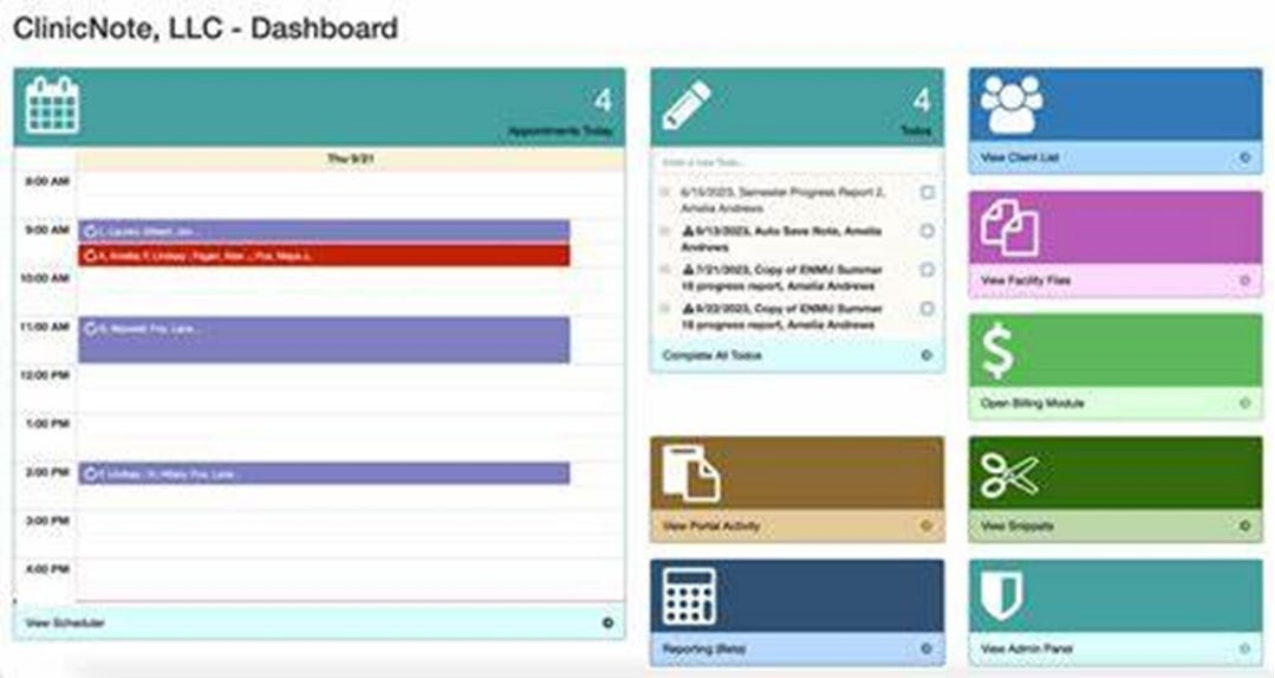
Amy Lyons-Brown	(760) 410-5312	alyons-brown@usa.edu
Name	Phone	Email

Voluntary Participation:
The purpose of this Activity has been explained to me and I know that being a part of this Activity is voluntary and I can withdraw my participation at any time with no penalty.

Communication/Telethealth: I consent to receive information (such as appointment reminders, patient surveys, and other information relating to the Activity) via the communication channels for which I provided the contact information including via phone, text, and email. I also consent to participate in telehealth care for some or all of my evaluation and/or treatment. Details of my medical history, examinations, x-rays, and tests will be discussed with other health care professionals and students through the use of interactive video, audio and telecommunication technology. A physical examination may not take place. A non-medical technician may be present in the telehealth studio to aid in the video

Telehealth

EMR

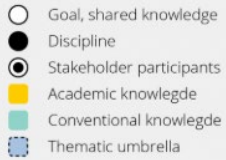

ClinicNote, LLC - Dashboard
4
Appointments Today
Thu 9/21
8:00 AM
9:00 AM
10:00 AM
11:00 AM
12:00 PM
1:00 PM
2:00 PM
3:00 PM
4:00 PM
View Scheduler
4
Today
Complete All Tasks
View Portal Activity
Reporting (Beta)
View Client List
View Facility Files
Open Billing Module
View Snippets
View Admin Panel

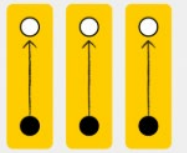

ClinicNote

The Experience of Using a Pro Bono Clinic to Provide OT Services

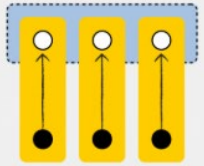
Service Delivery Model

Transdisciplinary Care

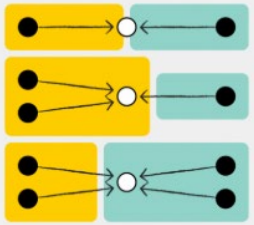




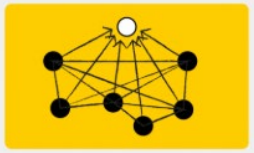
DISCIPLINARY
- Within one academic discipline
- Disciplinary goal seting
- Develops new disciplinary knowledge



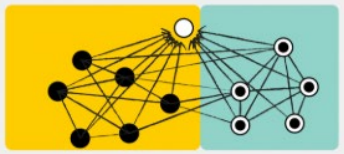
MULTIDISCIPLINARY
- Multiple disciplines
- Multiple disciplinary goals set under one thematic umbrella



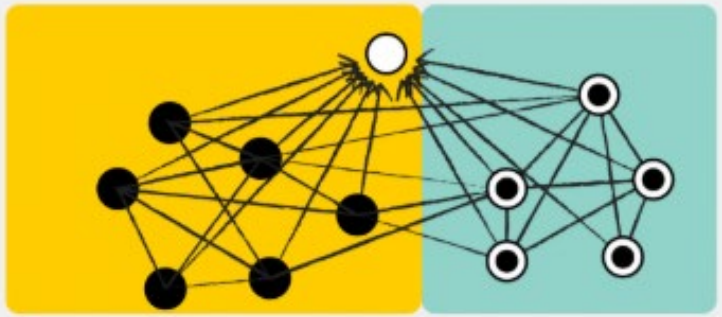
PARTICIPATORY
- Academic and non academic participants
- Knowledge exchange without integration



INTERDISCIPLINARY
- Crosses disciplinary boundaries
- Develops integrated knowledge
- Draws from and contributes to ‘inderdisciplines’



TRANSDISCIPLINARY
- Crosses disciplinary and sectorial boundaries
- Common goal setting
- Develops integrated knowlegde for science and society
- Draws from and contributes to ‘inderdisciplines’



TRANSDISCIPLINARY
- Crosses disciplinary and sectorial boundaries
- Common goal setting
- Develops integrated knowlegde for science and society
- Draws from and contributes to ‘inderdisciplines’

(Utrecht University, 2025)

Transdisciplinary Parenting Collaborative

Assessments for the Occupation of Parenting

ADL with Child
Dressing upper body
Dressing lower body
Feeding
Grooming & Hygiene
Bathing/Showering
Bathing Transfers
Diaper change/Toileting
Transfers to changing table
Transfers to toilet

Functional Mobility with Child
Baby wearing: Home environment
Community environment
Transfers baby/child:
• Bassinet/ Crib
• Baby bouncer/ Swing
• Crib
• Highchair
• Floor
• Car

Assessments for the Occupation of Parenting

IADL with Child
Meal preparation
Home Management
Laundry
Food Preparation
Shopping
Telephone
Finances
Medication
Transportation

IADL with Child
Baby/ Child Proofing
Health Management
Leisure/ Play
• Home-based
• Indoor community participation
• Outdoor community participation
Education

Assessments for the Occupation of Parenting

Craig Hospital Inventory of Environmental Factors (Chief)
Community Integration Questionnaire (CIQ)
Home and Community Environment Instrument (HACE)
Coping Health Inventory for Parents (CHIP)
General Self-Efficacy Scale (GSE)
Occupational Balance Questionnaire (OB-Quest)
Brief Pain Inventory (Short Form)
Tool to measure Parenting Self-Efficacy (TOPSE)

Marketing


Occupational Therapy Parenting Clinic
University of St. Augustine for Health Sciences
PRO BONO CLINICAL EXPERIENCES
Adaptive Parent Project
Telehealth service by appointment
Wednesdays 12 PM - 4 PM
*Currently open to CA residents.
More states coming soon!
What We Do:
Help parents with physical, sensory, or cognitive disabilities find practical, empowering solutions to daily challenges.
We Offer Support With:
• Adaptive strategies for home and parenting tasks
• Energy conservation and mobility techniques
• Memory, planning, and organizational skills
• Parenting tools and assistive devices
• Advocacy and resource navigation
Contact us:
Phone: 760-410-5312
Email: alyons-brown@usa.edu
AdaptiveParentProject@gmail.com

Marketing


Adaptive Parent Project
FREE ACCESSIBLE PARENTING CLINIC
Parents of all abilities are welcome!
Virtual appointments available for parents in California, more states coming soon
Wednesdays 12pm-4pm
For more information please contact
(760)-410-5312 alyons-brown@usa.edu
AdaptiveParentProject@gmail.com
UNIVERSITY of ST. AUGUSTINE for HEALTH SCIENCES
PRO BONO CLINICAL EXPERIENCES

Marketing


UNIVERSITY of ST. AUGUSTINE
for HEALTH SCIENCES
PRO BONO
CLINICAL EXPERIENCES
FREE
ACCESSIBLE
PARENTING
CLINIC
Wednesdays 12pm-4pm
Transdisciplinary Parenting
Collaborative
Adaptive Parent Project
zoom
Parents of all abilities are welcome
Virtual appointments available for parents
in California and Arizona, more states
coming soon
More Information
alyons-brown@usa.edu
(760) 410-5312
AdaptiveParentProject@gmail.com

Partnerships and Collaborations

- Adaptive Parent Project
- Wheelgood Motherhood
- Through the Looking Glass in Berkeley, CA
- Brandeis University: The Heller School for Social Policy and Management
- Washington University in St. Louis

The Use of a Pro Bono Clinic for FW Level I

“What moved me most as a Level I fieldwork student was seeing the client’s transformation, the way she felt safe, heard, and truly herself. Being in her own home through telehealth created comfort, but it was the presence of her advocate, Alesha, who validated her story and stood beside her, that opened the door for such honesty and trust. Witnessing this transdisciplinary care was not just powerful; it reminded me of the beauty and dignity that come when we meet clients where they are. I am especially grateful to Dr. Lyons-Brown, whose mentorship continues to inspire me to explore and advocate for the occupation of parenting.”

-Lauren Drochner

The Use of a Pro Bono Clinic for FW Level I

“Being part of the very first group of students in the pro bono clinic with the Adaptive Parent Project has been inspirational. This experience allowed me to actively bridge the gap for parents with disabilities and create space for support, advocacy, and opportunity. Being a part of a project so special not only shaped me as a future occupational therapist but also as a person, carrying forward a deeper sense of gratitude and purpose. I can’t wait to see this clinic grow!”

-Bianca Guevarra, OTS

Things we have learned so far

Community and Population

- Working with parents with disabilities is crucial
- Stigma
- Transdisciplinary Approach
- Limited knowledge of disabilities rights
- Safe health care providers
- Opportunities for collaboration
- Education for healthcare providers

Student Learning

- Application of classes
- Pull in beginning learning from classes into a real-world setting
- Development of critical thinking skills
- Advocacy

Interactive Stations

- Adaptive Clothing
- Feeding
- Baby wearing
- Strollers
- Car Seats
- Assistive Technology
- Harness
- Snuggle Bundle

References

VOLUME 1 OCTOBER 1, 2025

Navigating Parenthood with a Disability:

Practical Tips and Support

Photo credit: @Jessicaslice Image description: a toddler uses a wheelchair foot rest to climb up on his mothers lap.

Parenting with a Disability

Parenting with a disability can present unique challenges, from navigating physical tasks to balancing extra responsibilities. However, with the right tools, resources, and support parents can adapt and create a strong foundation for their families.

1

COMMUNITY

Connect with other parents with disabilities

2

CONNECTION

Connect with professions that are disability informed

3

RESOURCES

Tools to help you and your family thrive

Adaptive Parent Project

Empowering Parents with Disabilities

Wheel Good Motherhood

Free monthly peer support group for moms on wheels

University of St. Augustine for Health Sciences
PRO BONO CLINICAL EXPERIENCES

Free virtual OT clinic for parents with disabilities

Resources

Being disabled and having a child often requires more thought and practice when it comes to completing parenting tasks.

Scan the QR code below or click here to download helpful questions to ask your doctor about pregnancy and birth, parenting and disability organizations and books and disability inclusive baby/child items.

Photo Credit: @juliet.ah.justice
Image Description: A happy family of four people with different skin colors are smiling. They stand in front of a peach-colored wall with yellow and pink flowers. The mom is in a wheelchair in the middle and has a baby about one year old on her lap. The dad is on one knee to the left and is wearing a dark blue shirt. A little boy who is four years old is standing on the right and also wearing a dark blue shirt.

There are 65.9 million parents in the U.S and 4.4 million parents have disabilities (Sonik et al., 2018).

Reference

sonik, R. A., Parish, S. L., Mitra, M., & Nicholson, J. (2018). Parents with and without Disabilities: Demographics, Material Hardship, and Program Participation. Review of Disability Studies,14(4), 1–20. https://rdsjournal.org/index.php/journal/article/view/822

ADDITIONAL RESOURCES

Adaptive Parent Project

National Research Center for Parents with Disabilities

National Research Center for Parents with Disabilities

The Association for Sucessful Parenting

Through the Looking Glass

University of Saint Augustine Pro Bono Clinics

Wheel Good Motherhood Support Group

Image Description: Megan sitting in her wheelchair her desk writing in a journal. She is smiling with her up in a messy bun.
Photo Credit: megandejarnett