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FEED Safe: Functional Eating EDucation for Family Caregivers of Children with Disabilities in Lusaka, Zambia

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11/8/2021

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Doctor of Occupational Therapy Entry Level

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FEED Safe: Functional Eating EDucation for Family Caregivers of Children with Disabilities in Lusaka, Zambia

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Acronyms

CCG – Community caregivers
CDC – Center for Disease Control
CHW – Community health workers
CO-OP – Cognitive orientation to occupational performance
CP – Cerebral palsy
CWD – Children with disabilities
LMIC – Low- and middle-income countries
NGO – Non-governmental organization
OT – Occupational therapists
PFD – Pediatric feeding disorder
PT – Physical therapists or physiotherapists
QoL – Quality of Life
RCT – Randomized controlled trial
SLP – Speech and Language Pathologists
ToT – Trainer of Trainers
UN – United Nations
WFOT – World Federation of Occupational Therapists

Chapter One: Introduction

Background

A Global Snapshot

In 2020, Olusanya et al. estimated childhood disability to be 291.2 million children worldwide, with an estimated 275.2 million children with disabilities (CWD) living in low- and middle-income countries (LMIC). It is estimated that approximately 80% of children with developmental disabilities worldwide have feeding difficulties (Chatoor, 2009; Ramos et al., 2017; SPOON Foundation, 2020). In 2020, the Center for Disease Control (CDC) approved pediatric feeding disorder (PFD) to be a stand-alone diagnostic code in the 2021 International Classification of Diseases (ICD-11) (Feeding Matters, 2020). PFD is defined as "impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction" (Goday et al., 2019, p. 125). Children with PFD are at a higher risk for aspiration, undernourishment, and malnutrition. Families with a child with PFD in LMIC face barriers such as access to rehabilitative services, healthcare professionals trained in pediatric feeding, advanced technologies, and consistent supply of proper food (Goday, et al., 2019; Naal et al. 2020); World Health Organization, 2015).

Family caregivers of CWD in LMIC are reliant upon healthcare systems that are under-resourced (Naal et al., 2020). The World Health Organization (2021) predicts a global shortage of 18 million healthcare workers by 2030 with LMIC being most affected. Practitioner capabilities in continuing education, faculty, feeding technology, clinical space, and environmental resources are limited in LMIC (Naal et al., 2020). Therefore, in countries such as Zambia, equipping community health workers (CHW) and community caregivers (CCG) to train familial caregivers in best feeding practice becomes a necessity to achieve sustainable care for CWD.

Family caregivers need guidance in proper feeding techniques. Studies have shown that responsive caregiving is highly beneficial to a child's development across cultures and contexts (Mugode et al., 2018). Effective training models for program development contributes to knowledge translation from CHW and CCG to family caregivers, thus promoting the practice of appropriate feeding techniques to improve developmental outcomes (Colodny et al., 2015). Success in feeding can reduce the burden of disease, improve feeding performance and well-being, and promote family stability (World Health Organization, 2015). Therefore, it is necessary that familial caregivers receive training in evidence-based feeding strategies to improve health outcomes for their children.

A Global Target

The United Nation's 2030 Agenda for Sustainable Development outlined goals that aim to improve health equity globally including: 1) promoting well-being and ensuring healthy lives for all people of all ages; 2) achieving food security and improving nutrition; and 3) reducing inequalities (United Nations, 2015). Likewise, the World Federation of Occupational Therapists (WFOT) identified research goals that align with the 2030 Sustainable Development Goals (WFOT, 2016). WFOT's goals include: 1) directing research to develop effective occupational therapy interventions, 2) promoting evidence-based practice and knowledge translation, 3) promoting sustainable community development and population-based interventions, and 4) increasing participation in everyday life. The attainment of these goals has the potential to impact some of the world's most vulnerable people including CWD.

The Need in Zambia

Zambia is a large landlocked country in the South-Central region of Africa with a population of approximately 17.9 million people. In 2015, 53% of Zambians were under the age of eighteen and 4.4%

of Zambian children were living with a disability (Policy Monitoring and Research Center, 2020; UNICEF, 2021).

Zambia, like many countries, is facing a shortage of allied health workers. While Occupational Therapists (OT) and Speech and Language Pathologists (SLP) are leaders in treating PFD, as of 2016, there were only 3 SLPs and 3 OTs in Zambia to serve children with feeding difficulties (Bright & Selamani, 2017). Many of the CWD come from families living in poverty and with limited education (L. Hughey. August 16, 2021). Therefore, knowledge translation for best practice in feeding children with PFD must consider low-literacy rates and other environmental factors such as limited transportation and limited financial resources for feeding tools and equipment.

The Zambian government has positioned itself to partner with non-governmental organizations (NGOs) and faith-based organizations such as Catholic Medical Missions Board to improve the lives of Zambian citizens (L. Hughey. August 16, 2021). Alliances between the Ministry of Health, Ministry of Community Development, and NGOs position Zambia to implement community-based education programs for caregivers of CWD. Such alliances provide both human resources and tools to address the needs of familial caregivers of children with PFD (L. Hughey. August 16, 2021).

Zambia and many other LMIC are moving towards the reintegration of institutionalized CWD into the family unit (Catholic Relief Services, 2016). To promote family stability and reintegration familial caregivers of CWD require training in evidence-based feeding strategies (Catholic Relief Services, 2016). Such programming would likely decrease the risks of undernourishment, malnourishment, aspiration, and comorbidities secondary to feeding complications.

The Partner

SPOON Foundation, based in Portland, Oregon, partners with organizations and government entities globally to improve feeding practices for CWD. Through advocacy, training, and technology development, SPOON aims to reduce the burden of disease for CWD. SPOON envisions a world where all

children are nourished, valued, and thriving (SPOON Foundation, 2020). SPOON developed knowledge translation programs to promote best practice in mitigating pediatric malnutrition. SPOON's approach uses an empowerment model to train frontline workers evidence-based feeding strategies to improve pediatric developmental outcomes in low-resource settings (Hearst et al., 2014).

SPOON has had partners in seventeen countries. Currently, they have active projects in Zambia, Uganda, Tanzania, Haiti, Belarus, Vietnam, and the United States. Program assessment of SPOON's work in China, Vietnam, and India showed a significant decrease in stunting, anemia, and wasting in children served (SPOON Foundation, 2020). SPOON's work in Kazakhstan led to country-wide policy changes that improved the nutrition of children in institutional care leading to sustainability of evidence-based care in pediatric feeding at the institutional level (Miller, 2021).

The Project

The aim of this doctoral capstone project was to provide SPOON with a sustainable, culturally relevant training program for familial caregivers of children with PFD in Lusaka, Zambia. Dynamic systems theory, bioecological model, and adult learning theory provided the theoretical basis for the development of FEED Safe (Levac & DeMatteo, 2009). FEED Safe is a functional eating education program designed to train familial caregivers in evidence-based feeding techniques for CWD.

The FEED Safe Training Program includes: 1) the FEED Safe Trainer Manual to train community trainers, 2) the FEED Safe Flipbook to be used in training family caregivers, 3) and FEED Safe handouts to promote generalization of skills in the home. The FEED Safe Trainer Manual was designed using a trainer of trainers (ToT) model and adult learning theory for knowledge translation. The FEED Safe Flipbook was design using a community-based, multi-modal training model to promote caregiver networking. The cognitive orientation to occupational performance (CO-OP) model was integrated into the FEED Safe Flipbook to promote skill acquisition of evidence-based feeding techniques and improve the caregiver's

ability to problem solve feeding challenges (Polatajko & Mandich, 2004; Pierpont et al., 2020). Stages of project development included: 1) discovery, 2) development, and 3) delivery.

Review of Evidence

Disability and the Occupation of Feeding

Children with neurodevelopmental disabilities such as cerebral palsy (CP) often face a variety of issues that impact feeding such as decreased oral-motor ability, increased tone that impacts head positioning, sensory deficits, and communication deficits (Bruns & Thompson, 2012; Donald et al., 2014). Structural and functional deficits leave the child at an increased risk for aspiration pneumonia, reoccurring infections, and malnourishment that leads to stunting and wasting (Simpamba et al., 2020). When families lack the knowledge and resources to overcome feeding barriers, they are left with little choice but to relinquish caregiving rights and place children in institutionalized care (Sammon & Burchell, 2018). Countries aiming for reunification of CWD into the family unit should establish programming to train familial caregivers to meet the needs of children in a responsive manner (Catholic Relief Services, 2016; Mugode et al., 2017).

The Co-Occupation of Feeding

Feeding is a co-occupation that requires reciprocity between child and caregiver (Adams et al., 2012; Morris & Klein, 2000). For the child with a disability, the caretaker must adapt to the child's developmental ability and physiological capability to ensure successful feeding. If a child's caretaker is not trained in evidence-based feeding practices it increases the risk the child will experience a compromised airway or infection secondary to aspiration or vomiting, thus increasing the burden of disease (Goday et al., 2019; Simpamba et al., 2020; World Health Organization, 2015). Moreover, parents of CWD in LMIC, such as Zambia, often experience increased stress, exhaustion, social isolation, stigma, and reduced economic activity (Bunning & Thompson, 2017; Dambi et al., 2015; Nayer et al.,

2014; Singogo et al., 2015; Zuurmond, et al., 2018). In LMIC, lack of knowledge by a familial caregiver can impact occupational outcomes for the child with PFD which can lead to institutionalization (Williamson & Greenburg, 2010; World Health Organization, 2011). Knowledge translation is a key component of empowering families with CWD (Sudsawad, 2021).

Theories, Models, and Frameworks that Advance Knowledge Translation

The consideration of theories and models to guide the development of new programming is critical. Theories and models that do not address the needs of stakeholders will inevitably lead to program failure (Valters, 2015). Dynamic systems and ecological theories are widely utilized theories in healthcare and healthcare education at a global level (Schumway-Cook & Woollacott, 2012).

Program development that uses a bioecological model and dynamic systems theory has a greater likelihood of adequately addressing complex biopsychosocial problems and myriad of variables that accompany feeding CWD across cultures and contexts (Aprilia & Soendari, 2018; Den Besten et al., 2016; Donkor et al., 2019; Einfeld, et al., 2012; McLinden et al., 2018; Pierpont et al., 2020). Models and frameworks such as the ToT model, community-based rehabilitation and adult learning theory have been proven effective in LMIC (Adams et al., 2012; Aprilia & Soendari, 2018; Donkor et al., 2019; Einfeld, et al., 2012; McLinden et al., 2018). The CO-OP model has positive evidence supporting its use in the pediatric rehabilitation setting (Case-Smith & O'Brien, 2015; Pierpont et al., 2020). CO-OP has potential to be an effective model to equip parents to problem-solve feeding challenges and improve the occupational performance of feeding (Case-Smith & O'Brien, 2015; Pierpont et al., 2020). The use of established models for program development may increase the likelihood of knowledge translation from academia through community stakeholders to parental caregivers.

Significance and Innovation

Emerging Practice Areas

The presence of OTs in emerging practice areas, such as NGOs, may provide a stop-gap for the global healthcare shortage and improve poor feeding outcomes for CWD. OTs have expertise in identifying physiological, psychological and environmental barriers that contribute to poor feeding outcomes. Furthermore, occupational therapists who have attained a doctorate degree (OTD) have advanced training in social determinants of health, program development, and program assessment. This diverse set of skills positions OTDs to develop and implement programs in LMIC to educate caregivers, improve feeding practices, and improve health outcomes for CWD on a global scale. FEED Safe is a program that has potential to meet the need for caregiver education in the community providing a stop-gap for the shortage of rehabilitation specialists.

From Theory to Application

Each component of the FEED Safe program was designed with evidence-based theories and models to meet specific objectives to promote knowledge translation of evidence-based feeding strategies for parents of children with PFD in LMIC (See Table 1). The identification and implementation of effective training models for parenting children with PFD has the potential to increase parental self-efficacy (Hohlfield et al., 2018). Broader implications may include: a reduction in trial-and-error approaches during feeding sessions, a reduction in medical complications due to feeding difficulties, a decrease in caregiver stress, and an increase in participation in daily activities which improves developmental outcomes.

Furthermore, FEED Safe introduces a well-established occupational therapy model, CO-OP, in a new setting and context. The CO-OP model equips family caregivers in low-resourced settings to problem solve functional challenges that their children face. The CO-OP model has potential to

strengthen co-occupations of parents and their children (Pierpont et al., 2020). This innovative approach may expand the use of CO-OP beyond the OT clinic and show promise as a mechanism for knowledge translation and improved health in marginalized people groups.

Table 1.

Reasoning for Theories and Models Used in the Development of FEED Safe

Model	FEED Safe Training Manual	FEED Safe Flipbook	FEED Safe Handouts
Dynamic systems theory	• Addresses healthcare shortages • Uses available resources • Considers culture and context • Provides flexibility in programming	• Addresses healthcare shortage • Uses available resources • Considers culture and context • Provides flexibility in programming • Considers literacy • Promotes safe feeding practices	• Addresses healthcare shortage • Uses available resources • Considers culture and context • Considers literacy • Promotes safe feeding practices
Adult learning theory	• Allows participants to share existing knowledge • Provides a multi-modal learning experience	• Allows participants to share existing knowledge • Allows for experiential learning	--
Bioecological model	• Provides a holistic approach that promotes connection between trainers and caregivers	• Provides a holistic approach that recognizes the mind, body, and spirit of child and caregiver • Developmentally appropriate • Emotionally supportive • Culturally responsive • Uses available resources	• Developmentally appropriate • Promotes safe feeding practices • Uses available resources
ToT model	• Addresses healthcare shortage by training existing community members to disseminate knowledge	--	--
CO-OP model	--	• Promotes skill acquisition and generalization of skills by teaching problem solving	--
Community-based training model	• Addresses healthcare shortage by training existing community members to disseminate knowledge	• Uses available human resources, allows caregivers to build a support network • Provides a mechanism to share existing knowledge and resources	--

Contributes to the Attainment of Global Health Goals

In support of World Health Organization and WFOT goals, the FEED Safe training program enables the translation of knowledge that promotes occupational justice and health equity for the most vulnerable in society. Equipping family caregivers with evidence-based feeding strategies creates an opportunity for children with PFD to reintegrate into the family unit. Furthermore, FEED Safe aligns with the 2030 Sustainable Development Goals to promote good health and well-being (United Nations, 2015). As the child receives the necessary nutrients for metabolic functioning, s/he will also have increased opportunity to participate socially and engage in learning.

The effective training models used in FEED Safe promotes skill acquisition and self-efficacy that may increase participation in meaningful daily activities. Effective training has potential to reduce caregiver stress related to feeding sessions, increase nutrition intake, support a successful swallow, and reduce the likelihood of under-or malnourishment (Adams et al., 2012; Colodny et al., 2015; Zuurmond et al., 2018). In turn, caregiver and child quality of life (QoL) may also be improved.

Objectives

Three objectives were identified for this capstone project. The first was to develop a training manual based on the well-established ToT model and adult learning theory for training familial caregivers in evidence-based strategies to improve feeding outcomes for children with PFD. The FEED Safe training manual would provide a mechanism for knowledge translation between academia and well-trained health-care provider to community-based healthcare and human service providers in low-resourced communities.

The second objective was developing a flipbook for CHW or family trainers that incorporates the CO-OP model as a mechanism for knowledge translation during face-to-face training with familial caregivers. Several key considerations were accounted for during the development of the FEED Safe

Flipbook including culture, societal values, norms, and literacy. A multi-modal, community-based approach was used in the development of the FEED Safe Flipbook.

The third objective was to create culturally relevant supplemental handouts for best feeding practices to support generalization of new skills in the home setting. Handouts could later be incorporated into a mobile app to support caregivers in the home or disseminate information throughout the community or to other target markets.

Chapter Two: Scoping Review

Introduction

Familial caregivers of children with PFD in LMIC face a variety of challenges that impact the nutritional intake and mealtime success. Limited access to healthcare professionals trained in PFD, limited education in safe feeding, a child's physiological barriers, and environmental factors all impact a caregiver's ability to feed their child safely and appropriately (Adams et al., 2012; Aprilia & Soendari, 2018). Through identifying training models that are effective, practitioners and CHW can develop effective programs to train familial caregivers of children with PFD in evidence-based feeding strategies. Success in feeding can help reduce the burden of disease, improve occupational performance and well-being, and promote family stability (World Health Organization, 2015).

Research Priorities for Occupational Therapy Research

The aim of the scooping review was to identify evidence-based training models that facilitate knowledge translation and implementation of best practices from provider to familial caregiver of the child with PFD in LMIC. The identification and implementation of effective training models for parenting children with PFD has the potential to increase parental self-efficacy (Hohlfield et al., 2018). Broader implications may include: a reduction in trial-and-error approaches during feeding sessions; a reduction in medical complications due to feeding difficulties; and increase in participation in daily activities which improves developmental outcomes.

This scoping review contributed to UN sustainable development and WFOT goals by identifying evidence for theoretical models in program development for feeding interventions to improve health outcomes for children in LMIC. Likewise, evidence found in this scoping review can contribute to program development that translates knowledge successfully and promotes sustainable community

development programs. Programs using valid theories can improve occupational performance for both child and caregiver.

Scoping Review Question

What evidence-based training models best support familial education of PFD in LMIC?

Methods

A review of literature was conducted using CINAHL Plus Full Text, PubMed, APA PsycInfo, Google, Google Scholar (scholar.google.com), UNICEF (unicef.org), American Journal of Occupational Therapy (AJOT.org), World Federation of Occupational Therapy (WFOT.org), WHO (WHO.org), and ProQuest Dissertations & Theses Global. The search included primary evidence and grey literature. Forty-five articles were relevant to identifying evidence-based models for training parents of children with PFD in LMIC. Ten of the most relevant articles were chosen for initial appraisals. Three were selected for critical appraisals. Inclusion criteria consisted of one or more of the following:

- LMIC
- children with a physical disability, PFD, or intellectual disability
- training model or framework used for parent training of children with disabilities
- articles that explicitly stated or inferred an underlying model or framework for a program/intervention that was being tested to improve parental care of children with disabilities
- primary research on caregiver training programs

Initial selection of articles was based on quality of evidence, relevance to contextual factors that impact LMIC, potential impact to improve caregiver QoL translational quality to improve intervention outcomes, integrity and authority of publisher, and cultural fluidity. Coherence with the UN Sustainable Development Goals 2030 and the United Nations Convention on the Rights of People with Disabilities

(CRPD) (Convention on the Rights of Persons with Disabilities (CRPD), 2007; UN, 2015). Literature selected for critical appraisals had moderate to strong evidence to support using a model for the development of a parent training program of pediatric feeding disabilities in LMIC.

Results

A total of 10 articles were retained for the scoping review. Despite a robust search, there was a paucity of research directed towards verifying the efficacy of models. Few studies in the search explicitly state a theoretical basis that informed the tested intervention. However, many of the interventions reflected a dynamic system theory, took an ecological approach, and gave enough information to associate existing models. If a model or framework was explicitly stated, then one could infer the model's success based on the success of the intervention. It should be noted that there is a risk for bias toward one model over another based on the prevalence of the model being presented as a theoretical basis in research.

Seven articles were categorized as primary research, two articles were reviews of research, and one article was theoretical (see Table 2). Of the seven primary research studies, one study took place in Sri Lanka (Hettiarachchi et al., 2018), one took place in Guatemala (Colodny et al., 2015), two took place in Ghana (Donker et al., 2018; Zuurmond et al., 2018), one took place in Indonesia (Aprilia & Soendari, 2018), one took place in Bangladesh (Adams et al., 2012), and one took place in Tanazania (Mlinda et al., 2017). The studies included in the conceptual review were from LMIC and included Zimbabwe, India, Turkey, and Lesotho (Einfeld et al., 2012). The systematic review articles included studies from the USA, Canada, Spain, United Kingdom, Iran, China, Norway, Australia, Sweden, Netherlands, Denmark, United Arab Emirates, Germany, Turkey, and Brazil (Sheng et al., 2018). One theoretical article was applied to longitudinal research in Malawi (McLinden et al., 2018).

The articles chosen for this study were retrieved from scholarly peer-reviewed journals published in the US and globally (see Table 2). Eight of the articles were published between 2015-2020.

Two articles were published between 2011-2012. Articles included in the review consisted of two descriptive qualitative studies, one randomized controlled trial (RCT), one single descriptive quantitative study, three mixed-methods studies, one conceptual review, one systematic review/meta-analysis, and one theoretical article embedded in an ongoing longitudinal mixed-methods study.

Of the two descriptive qualitative studies, one had three caregiver participants and the second consisted of child/caregiver pairs (n=16 children,15 caregivers). Participants in the RCT consisted of child/caregiver pairs (intervention n=63; control n=47). The quantitative single descriptive case study trained public health midwives (PHM) as a multi-disciplinary approach to address needs (n=38). Of the three mixed-methods studies chosen, two selected caregiver/child pairs for the studies (n=75 and n=37). The remaining mixed-method study utilized multi-disciplinary teams to evaluate a training model (n=205 interdisciplinary healthcare professionals). Sample size of the conceptual review ranged from 6 to 450 parents of children with intellectual disabilities in LMIC. The systematic review sample size range was 13 to 446 child/caregiver pairs across low-, middle-, and high-income countries. The remaining article was a theoretical article that is the foundation for an ongoing longitudinal mixed-methods study taking place in community-based childcare centers across Malawi.

Donkor et al.'s (2019) descriptive study utilized pre-intervention interviews. Participants attended one year of monthly group trainings and home visits. Getting to Know Cerebral Palsy was utilized as training curriculum. Post-intervention interviews and observations were conducted, and researchers identified six recurring themes related to caregiver's experience of feeding a child with CP. Aprilia and Soendari's (2018) descriptive qualitative study utilized three stages. First, the author's gathered data of familial conditions through interview, observations, and documentation. Second, the author's designed an ecological framework to guide interventions for families of children with disabilities. This stage utilized data from focus group discussions as well as a needs analysis. Finally, trial

model was implemented, and the authors gathered information on feasibility and acceptability to the families (Aprilia & Soendari, 2018).

Mlinda et al.'s (2017) RCT trained utilized both group and individual sessions to train caregivers about nutrition, positioning for feeding, and occupational therapy techniques to improve feeding outcomes. Illustrations depicted safe feeding practices and were utilized to increase participant knowledge. The single descriptive quantitative study by Hettiarachchi et al. (2018) utilized small multi-disciplinary teams to train 38 PHM in dysphagia management. Training included educating the PHM about CP and its associated difficulties, phases of a normal swallow, normal development of eating and drinking skills, signs and symptoms of dysphagia and aspiration. Training also included key strategies to improve feeding outcomes for children with PFD such as modifying food texture, pacing, positioning, and utilizing modified utensils (Hettiarachchi et al., 2018).

Two mixed-methods studies conducted group/community-based interventions to train caregivers (Adams et al., 2012; Zuurmond et al., 2018). One mixed-method study focused on program implementation and included a variety of stakeholders and multi-disciplinary teams (Colodny et al., 2015). Colodny and colleagues (2015) recruited over 205 individuals from different disciplines and gathered data through pre-post interviews, observations, and pre-post assessments. Qualitative analysis was used to derive themes that would drive program development and impact the intervention. Descriptive statistics were used to measure improvement in recognition of dysphagia signs and symptoms.

The reviews investigated familial impact of caregiver training and sustainable interventions (Sheng et al., 2019; Einfeld et al., 2012). Sheng et al.'s (2019) systematic review was more comprehensive (n=54) but included studies from high-income countries. Einfeld and colleagues (2012) produced a smaller conceptual review (n=7); yet this review included only research from LMIC. It is well-

established in scholarly literature that few studies exist examining familial training of pediatric disabilities in LMIC (Adam et al., 2011).

Table 2.

Frequency Analysis of Caregiver Training Models (n=10)

Criteria		Number of Studies
Study Design	Qualitative	2
	Descriptive	2
	Quantitative	2
	Randomized Control Trial	1
	Single Descriptive	1
	Mixed-Methods	3
	Research Review	2
	Conceptual Review	1
	Systematic Review/Meta-analysis	1
	Theoretical Articles	1
Source of Publication	Scientific, Social Science, Education	3
	Disability	2
	Child Development	3
	Therapy	1
	Nutrition	1
Participants	Familial Caregivers	5
	Nursing/Midwives	1
	Interdisciplinary Teams	3
	Community-Based Child-Care Center	1
Models	Community-Based Training Model (Explicitly Stated)	3
	Bioecological or Ecological Model (Explicitly Stated/Inferred)	4
	Parent-Group Model (Explicitly Stated)	1
	PRECEDE-PROCEED Model (Explicitly Stated)	1

Summary of Themes

The purpose of this scoping review was to search the literature for potential models for program development that would support caregiver training for children with PFD in LMIC. Experimental research on the efficacy of models is rare due to the theoretical nature of models. However, qualitative review of

primary research of interventions provides a mechanism to derive themes that should be included when deciding a model for program development. This review identified four themes:

- The model should allow for a multi-modal approach to training familial caregivers about PFD
- The model should allow for a community-based approach to training familial caregivers about PFD
- The model should allow for multi-disciplinary teams to be involved in training familial caregivers about PFD
- The need for an ecological model to mitigate barriers and promote sustainability of familial caregiving interventions for PFD

This scoping review revealed efforts to effectively address healthy development and inclusive practice for children with disabilities in LMIC. Emergent themes include:

- Community-Based Inclusive Development
- Community-Based Rehabilitation
- A need for parent training
- The effectiveness of ecological and bioecological models to address physical and environmental barriers of the child and family.
- Current published frameworks, such as The Nurturing Care Framework is interdisciplinary and family centric (World Health Organization, 2018).

Theme 1: Multi-Modal Instruction

Studies showed the effectiveness of multi-modal instruction for familial caregivers of children with disabilities in LMIC. All of the studies (n=10) included in this scoping review described elements of multi-modal instruction (Adams et al., 2012; Aprilia & Soendari, 2018; Colodny et al., 2015; Donkor et al., 2019; Einfeld et al., 2012; Hettiarachchi et al., 2018; McLinden et al., 2018; Mlinda et al., 2018; Sheng

et al., 2018; Zuurmond et al., 2018). A multi-modal program for adult learning considers various learning styles, educational achievements, literacy rates, and cultural norms. Examples of multi-modal program materials include printed material, visual aids, illustrations, verbal instruction, demonstration, face-to-face learning, and hands-on practice. Additionally, multi-modal instruction can take place in a variety of community-based settings such as hospitals, community health clinics, and community-based child-care centers (Mlinda et al., 2018; McLinden et al., 2018). A conceptual review by Einfeld et al. (2012) determined the need to adapt training programs for use in LMIC. Training media developed for familial caregivers in LMIC should conform to cultural differences, reduce expensive technologies, and account for urban and rural distribution.

Studies indicated that multi-modal instruction promoted skill acquisition (n=11). In a mixed-methods study conducted in Bangladesh that included 37 familial caregivers and their children, Adams and colleagues (2012) found that traditional pedagogy, discussion, kinesthetic approaches that utilized video dramas and other visual aids contributed to the success of the training intervention. Participants practiced adapting food consistency, positioning of their child, and using appropriate tools. Through modeling, hands on practice and discussion, participants were able to improve feeding skills and learn techniques to support their child in self-feeding. This approach was found to be successful in Mlinda and colleagues (2018) randomized control trial (intervention n=63 and control n=47) when caregivers received supplementary illustrations as reference sheets to support skill acquisition of feeding techniques. Illustrations were culturally relevant to Tanzanians and depicted common social and ecological conditions.

Multi-modal instruction shows potential for improving caregiver or child QOL (n=9) (Adams et al., 2012; Aprilia & Soendari et al., 2018; Colodny et al., 2015; Donkor et al., 2019; Einfeld et al., 2012; McLinden et al., 2018; Mlinda et al., 2018; Sheng et al. 2018; Zuurmond et al., 2018). Sheng et al. (2019) conducted a systematic review and meta-analysis which included studies that used multi-modal

instruction. The authors determined face-to-face interventions significantly improved health-related QoL (Sheng et al., 2019). This finding suggests that face-to-face multi-modal instruction provides caregivers with adequate knowledge to make positive contribution to the care of their child and improve the child's health outcomes. Mlinda and colleagues (2018) also found that caregivers in the intervention group (n=63) had significantly less stress after the intervention (p=0.049). Hettiarachchi and colleagues (2018) utilized multi-modal instruction to connect theory to practice in a study of 38 PHM. The PHM that participated in a single descriptive case study reported an increase in perceived knowledge and self-reported confidence in safe feeding strategies when multi-modal instruction was utilized (Hettiarachchi et al., 2018).

Multi-modal instruction contributed to improved feeding outcomes that impacted both children and caregivers/ (n=4) (Adams et al., 2012; Donkor et al., 2019; Mlinda et al., 2018; Zuurmond et al., 2018). Mlinda and colleagues (2018) reported significant improvement in feeding positioning ($P < 0.001$), feeding speed ($P < 0.001$), and increased child-involvement ($P < 0.01$) was found in the intervention group. Adams et al. (2012) showed improvement in child feeding skills ($P < 0.001$) and a perceived reduction in mealtime ($P < 0.001$).

Theme 2: Community-Based Interventions

Five primary research articles, one conceptual research, and one theoretical article emphasized the benefits of community-based programs for caregiver training of feeding and caring for children with disabilities (Adams et al., 2012; Colodny et al., 2015; Donkor, et al. 2019; Einfeld et al., 2012; Heittiarachchi et al., 2018; McLinden et al., 2018; Mlinda et al., 2018; Zuurmond et al., 2018). Studies indicated that a training model that supports community-based interventions provides a mechanism for knowledge translation in low resource settings, promote community and peer support, and contributes to improved feeding outcomes.

Community-based interventions promote knowledge translation in low-resource settings. Studies indicated that professionals, para-professionals, and familial caregivers could be trained in best practices for feeding children with disabilities (Adams et al., 2012; Colodny et al., 2015; Donkor, et al. 2019; Einfeld et al., 2012; Heittiarachchi et al., 2018; McLinden et al., 2018; Mlinda et al., 2018; Zuurmond et al., 2018). A conceptual review including seven studies found that a train-the-trainer approach can be utilized to train individuals throughout the community including professionals and familial caregivers (Einfeld et al., 2012). Donkor and colleagues (2019) provided community-based training for improving the nutritional status of children with CP across eight geographical regions in Ghana. Post-intervention observations showed caregivers (n=11) attention to improving the child's positioning at mealtimes (Donker et al., 2018).

Community-based interventions promote community and peer support. Zuurmond and colleagues (2018) recruited 75 familial caregivers across eight regions in Ghana for a mixed-methods study. Familial caregivers were placed in groups that used a participatory approach that promoted problem solving and peer support (Zuurmond et al. 2018) Likewise, Donker and colleagues (2018) interviewed eleven familial caregivers of children with CP after one year of receiving community-based group trainings. Participants reported positive feelings about connecting with other caregivers of children with CP (Donker et al., 2018).

Community-based interventions may contribute to improved feeding outcomes for children with disabilities in LMIC. Adams and colleagues (2012) reported a reduction in child distress during feeding ($P = 0.06$), an increase in fluid intake ($P < 0.01$), a reduction in fussiness ($P < 0.005$), a reduction in food refusal ($P < 0.003$), and improved nutritional status (mean weight for age, $P < 0.02$; mid-upper arm circumference, $P < 0.001$). In another study of 75 primary caregiver-child pairs who received a community-based intervention a significant number of parents reported improvement in problems in the domains of child eating and drinking, self-feeding, and needs help feeding (Zuurmond, 2018).

Theme 3: Multi-disciplinary Teams

This scoping review revealed the potential for models that support the use of multi-disciplinary teams as an avenue for knowledge translation in LMIC and utilize available human capital (Aprilia & Soendari, 2018; Colodny et al., 2015; Heittiarachchi et al., 2018). Availability of health care workers will vary across countries and communities, thus multi-disciplinary teams take advantage of the diversity of available human resources (Colodny et al., 2015). Across the ten articles in this scoping review facilitators consisted of twelve professions: medical doctors, occupational therapists, physiotherapists, physical therapists, physiotherapy assistants, generic therapists, speech and language pathology graduate students, auxiliary nurses, trained nurses, directors of nursing, nutritionists, and public health midwives (Adams et al., 2012; Aprilia & Soendari, 2018; Colodny et al., 2015; Donkor et al., 2019; Einfeld et al., 2012; Hettiarachchi et al., 2018; McLinden et al., 2018; Mlinda et al., 2018; Sheng et al., 2018; Zuurmond et al., 2018). Reported education level of facilitators varied from 5th grade to post-graduate (Colodny et al., 2015). Adams et al. (2012) recognized that interventions in LMIC may be facilitated by non-specialist workers or healthcare professionals without advanced training in pediatric feeding disabilities. Colodny, Miller, & Farelli (2015) utilized the PRECEDE-PROCEED model and engaged a multi-disciplinary team (n=102) to improve feeding techniques for 103 children with PFD. Positive outcomes such as reduced stress around feeding times were noted when familial caregivers were considered valuable members of the team (Donkor et al., 2019, Einfeld et al., 2012).

Theme 4: The Need for an Ecological Model to Mitigate Barriers and Promote Sustainability

Studies reviewed indicated that LMIC face resource challenges that may cause barriers to sustainability of training interventions for familial caregivers of children with PFD (Adams et al., 2012; Colodny et al., 2015; Aprilia & Soendari, 2018). Barriers identified in this scoping review include:

- Limited availability of trained rehabilitation specialists (occupational therapist, speech language pathologists) to provide rehabilitative service to children with PFD (Einfeld, 2012; Hettiarachchi et al., 2018)
- Limited or inadequate knowledge of evidence-based feeding interventions (Colodny et al. 2015; Donker et al., 2018; Hettiarachchi et al., 2018)
- Lack of knowledge of dysphagia signs and symptoms (Colodny et al., 2015; Hettiarachchi et al., 2018)
- Limited financial resources impact the acquisition of tools and technology (Colodny et al., 2015)
- Availability of training material (Aprilia & Soendari, 2018)
- Lack of financial infrastructure to support expensive interventions (Adams et al., 2012)
- Time limitations for preparing special diets (Adams et al., 2012)
- Availability of supplemental nutrition sources and nutrient dense sources (Adams et al., 2012; Einfeld et al., 2012; Zuurmond et al., 2018)

Three primary research articles and one theoretical article emphasized the ability of ecological or bioecological models to address existing socioeconomic or environmental barriers limiting the sustainability of training interventions and caregiver skill acquisition (Adams et al., 2012; Aprilia & Soendari, 2018; McLinden et al., 2018; Mlinda et al., 2018). A bioecological model considers the gene-environment interaction and accounts for biopsychosocial variables. Aprilia and Soendari (2018) conducted a needs analysis of familial caregivers of children with disabilities to identify limitations in resources that would affect outcomes of familial training interventions. Two studies reported community-based training programs can be implemented for a low-cost (Adams et al., 2012; Einfeld et al., 2012). Einfeld and colleagues (2012) highlighted the need for supplemental nutrition programs from children with disabilities. McLinden et al. (2018) suggested a bioecological approach to address barriers while Colodny and colleagues (2015) utilized the PRECEDE-PROCEED model to address barriers by

identifying predisposing, reinforcing, and enabling factors. After the identification of factors, Colodny and colleagues were able to take advantage of available resources to design a program for the specific community (Colodny et al., 2015).

Discussion

Findings from this scoping review can be used to inform program development for familial training programs for children with PFD that live in LMIC. This review revealed the importance of utilizing multi-modal educational methods, the effectiveness of community-based models, the value of multi-disciplinary teams, and the need for a bioecological approach to address barriers and promote sustainability of familial caregiver training interventions. This research has implications for non-governmental organizations as they identify practical models for the development of training programs in LMIC. Likewise, occupational therapists who work in LMIC can use this information to address occupational injustice and promote best practices. Government entities and healthcare systems in LMIC can utilize this knowledge to engage in achieving Sustainable Development Goals as they build effective social and health care systems to address the needs of familial caregivers of children with PFD.

This scoping review verified the limited scope of research related to training models for PFD in LMIC. However, the themes that were extracted from the review reveal both needs and opportunities for training familial caregivers of children with PFD. While this review of literature is intended to inform practice in LMIC, there are many takeaways that could apply globally regardless of socioeconomic status.

Implications for Practice

Multi-Modal Instruction

A multi-modal approach to instruction contributes to translation of feeding-best practices and provides a mechanism for consistent instruction across facilitators (Mlinda et al., 2018). Additionally,

familial caregivers of children with PFD in LMIC vary in training needs based on education, the availability of tools and technology, and the population of trained health care providers (Adams et al., 2012; Einfeld et al., 2012; Heittiarachchi et al., 2018; Mlinda et al., 2017). Multi-modal instruction can address a variety of needs for the given context and setting. Furthermore, multi-modal instruction can account for lack of resources by creating sustainable low-cost solutions to train parents in various contexts (Einfeld et al., 2012; Heittiarachchi et al., 2018).

Community-Based Interventions

Community-based interventions can promote knowledge translation of best practice for PFD in a setting that has limited access to rehabilitation professionals (Zuurmond et al., 2018). Community-based interventions built on bioecological models have the potential to mitigate barriers and promote development for children with disabilities (McLinden, 2018). Also, community-based interventions have the potential to improve caregiver QOL (Zuurmond, 2018). Intervention platforms that are community-based promote sustainability because they utilize available human resources and take advantage of community infrastructure (Adams, 2012; Einfeldet al., 2012; McLinden et al., 2018; Hettiarachchi et al., 2018).

Multi-disciplinary Teams

Multi-disciplinary teams provide a mechanism for knowledge translation of best-practice for feeding children with PFD in resource limited environments (Colodny et al., 2015). There is significant power in the parent-child dyad that should be considered when building multi-disciplinary teams (Adams et al., 2012; Einfeld et al., 2012; Donkor et al. 2019). The familial caregivers and the child are the most integral part of the team. Multi-disciplinary teams have the potential to contribute to behavior change in familial caregivers of children with PFD which may lead to improved QOL and reduced stress around feeding times (Donkor et al., 2019). Moreover, multi-disciplinary teams contribute to

sustainability when using a train the trainer approach that allows parents to train other parents (Einfeld et al., 2012).

Mitigating Barriers & Promoting Sustainability of Training Interventions

Bioecological models may provide a platform to address environmental barriers and create sustainability of a training intervention (Aprilia & Soendari, 2018; McLinden et al., 2018). Training interventions for familial caregivers of children with PFD should consider the availability of local programs, such as supplemental nutrition programs, that may benefit families by providing needed resources (Adams et al., 2012; Einfeld et al., 2012). Bioecological models account for the dynamic relationship between a familial caregiver of a child with a disability and their environment (Aprilia & Soendari, 2018).

Another step to sustainability is to conduct a needs analysis to identify barriers that would affect the outcome of training interventions (Aprilia & Soendari, 2018). An effective model for program development should account for demands on caregiver's time (Adams et al., 2012). An appropriate model should also account for limited support from the healthcare sector (Adams et al., 2012; Einfeld et al, 2012).

Implications for Occupational Therapists

Occupational therapists (OTs) are uniquely positioned to improve PFD world-wide. Many occupational therapy models and frameworks are built upon bioecological models that account for a dynamic interaction between a person and their environment. OTs are also skilled analysts who logically and methodically develop intervention plans that reduce barriers and improve occupational performance. OTs also understand the power that exists in the parent-child dyad and often use approaches that improve outcomes for both caregiver and child. These qualities make them good candidates for program development as well as advocacy.

Recommendations

Non-governmental organizations, rehabilitation therapists, and other healthcare professionals working in LMIC face many barriers when developing training interventions for familial caregivers of children with PFD. Moreover, training interventions for familial caregivers of children with PFD in LMIC should be culturally relevant and appropriate to aid in acquisition of new behaviors. For completion of a doctoral capstone project, the following recommendations are intended to inform program development for SPOON while promoting best practice and sustainability of the interventions in LMIC.

1. Adapt an existing occupational therapy model to inform program development that supports a dynamic and bioecological approach to feeding interventions in LMIC.
2. Conduct a needs analysis in each community served to determine predisposing, reinforcing, and enabling factors. The needs analysis will expose barriers to sustainability. Engage community stakeholder to access available resources such as supplemental nutrition programs, tool acquisition, or reproduction of training materials.
3. Develop training interventions utilizing a multi-modal approach that can be tailored to communities based on available resources. Consideration must be made to ensure a community has local resources to duplicate printed materials, manufacture or acquire needed tools, and maintain technology for audio-visual media.
4. Expand training in existing markets for familial caregivers and local healthcare providers as part of a multi-disciplinary team to promote knowledge translation of best practice in feeding children with disabilities and encourage reintegration of institutionalized children into a family setting.
5. Utilize a community-based approach in which parents are integral members of the team. Consider the use of train-the-trainer approaches while developing community-based support

groups for parents; thus, strengthening the parent-child dyad by improving the familial caregiver's psychosocial health.

Occupational therapists are well-suited and positioned to implement the above recommendations.

Conclusion

The creation of sustainable, culturally relevant programs to train familial caregivers of children with PFD in LMIC is a complex undertaking. It is critical to take a dynamic and bioecological approach. Consideration of beliefs, attitude, and values of the caregivers, the various abilities of children that may be served, and the availability of tools and resources are necessary for a program to contribute to positive health outcomes. Through the use of a dynamic and bioecological approach to program development, those developing new programming can discover the needs of stakeholders before developing educational materials.

Chapter Three: Needs Assessment

Methods

Prior to beginning the capstone experience, a needs assessment was completed to understand gaps in SPOON programming. Data was acquired through review of organizational data (SPOON database), review of current programming (Count Me In), and literature review. Interviews were conducted with SPOON staff in the United States and an executive technologist competent in digital platforms for knowledge translation to determine SPOON service gaps and technical feasibility.

Interviews

An interview was conducted with SPOON program officer, Kate Miller, SLP, to answer questions related to current projects, organizational goals, barriers that impact service, and potential stakeholders (see Appendix A, Table A1). Organizational goals and scope of project were discussed. The interview took place over 2 days (1 hour the first day and 1 hour 40 minutes the second day). The video chat was conducted via Zoom and recorded for reviewal purposes. Information was gathered to assess:

- organizational needs in SPOON's active programs
- previous and current training/interventions that SPOON has/is engaged in
- gaps in service with partner organizations
- stakeholders
- potential populations to be served
- barriers: clinical, geographical, cultural, technological,
- current and prospective models and frameworks for training caregivers

Ms. Miller reviewed the current programs and partners. She discussed the need for training specific to familial caregivers. Zambia and Uganda were identified as best-fit partners for the project.

The national language of Zambia and Uganda is English. Current barriers include COVID-19 quarantines, travel restrictions, language barriers (indigenous languages), and transportation time for caregivers.

An additional interview was conducted with Matt Fairchild, VP of Technology Operations North America at Wunderman Thompson, to discuss feasibility and barriers of Mobile App development for knowledge translation in LMIC (See Appendix A, Table A2). Mr. Fairchild has over 20 years' experience in the development of web-based and mobile apps, architecture, user-experience design, and leading teams to create applications to client specifications. Technical discovery included:

- Differences between a web application and a mobile app
- Differences between platforms (android, apple, etc.)
- Geographic and contextual variables such as downloadable content vs. cloud-based content
- Barriers such as internet connectivity and stable networks
- Translation and language barriers

Initially it was thought that the development of a mobile app would be beneficial. However, the interview process with Ms. Miller and Mr. Fairchild revealed that precursory multi-modal community-based training in print would be most appropriate for the current target market. This print version would provide knowledge and best practices that could later be translated to a mobile app when ecologically appropriate.

Review of Organizational Data & Public Records

SPOON's organizational data was reviewed to gather information on physiological conditions that impact feeding outcomes for the population served. A review of Count Me In resources supplied information on international growth and development standards, feeding strategies, food texture and medication, and breastmilk safety and alternatives. The *Count Me In* Learning modules (web-based and text) provided information on current best-practices in the areas of feeding and growth monitoring.

Count Me In coursework for nutrition standards and developmental feeding skills was reviewed. In primary research on segmental trunk control in CP was reviewed to gather information on evidence-based practice in postural control for feeding (Saavedra & Woollacott, 2015). Information on ToT model was gathered from the CDC A review was conducted of *Feeding the Disabled Child* to gather information on best practice in feeding (Sullivan & Rosenbloom, 1996). This is a seminal work used to guide feeding practices by SPOON.

Data and Themes

Information gathered from stakeholder interviews and organization databases revealed the SPOON partners serve children with a variety of disabilities (Table 3). The CWD that SPOON serves face functional deficits that impact feeding outcomes (Table 4). Current SPOON programming targets caregivers of children with disabilities at an institutional level. At the time of the needs assessment the SPOON resource library included topics on food textures, specialized feeding techniques, aspiration, positioning, growth monitoring, anemia, and breast milk and breast milk alternatives. Currently SPOON has developed learning modules about anemia, mealtime best practices, developmental feeding skills, nutrition, growth monitoring, introduction to disability, measuring hemoglobin, positioning, screening for feeding difficulties, specialized feeding techniques, and strategies for feeding infants. The target audience for these resources were caregivers with a literacy level of 8th grade and above.

Table 3.

Diagnoses of Children Served by SPOON Partners

Condition	Approximate Percent of Population Served
cerebral palsy	54
cognitive impairment	8.8
seizure disorder/epilepsy	6.3
Down syndrome	5.9
hydrocephalus	5.2
premature birth	3.3
heart disease	2.9
autism spectrum disorders	2.5
HIV/AIDS	2.3
visual impairment	1.6
cleft lip/palette	0.7
other conditions	29

Table 4.

Conditions and Symptoms Affecting Feeding Outcomes in Target Populations

Sensory	Strength, Posture, and Endurance	Oral Motor	Swallowing, Digestion, & Absorption
Hypersensitivities	Hypertonicity	High or Low tone in facial muscles	Aspiration
Hyposensitivities	Hypotonicity	Tongue thrust	Oral Lesions
Misinterpretation of Hunger and Thirst Cues	Poor Strength	Poor suck, swallow, breathe synchrony	Reflux
Visual Impairment	Cardiopulmonary conditions	Inability to regulate flow	Diarrhea
Communication Impairment	Apnea/Bradycardia	Tongue tie	Constipation
Developmental Delays	Respiratory Distress	Drooling/Inability to retain food in mouth	
Retention of Primitive Reflexes		Poor tongue lateralization	

SPOON has recognized the global effort for reintegration of children with disabilities into family care. This would require expanding training opportunities beyond clinical and institutional settings to

reach familial caregivers of CWD. Yet, there are barriers that SPOON must address to successfully ensure knowledge translation in best feeding practices for CWD. A SWOT analysis was conducted to provide insight into potential assets for program development and barriers that may arise during the course of the project (see Table 5).

Geographical barriers such as ease of transportation to rural areas in Vietnam would need to be addressed. In Haiti, political unrest has led to roadblocks and safety issue when traveling from one area of the country to another. Internet accessibility is more difficult in rural regions of Uganda, Zambia, Vietnam, and Haiti which limits the effectiveness of any cloud-based training platform. Cultural barriers are also important to consider. Many of the countries that SPOON serves have myths about the origin or nature of disability. These beliefs may be tied to religious or spiritual practices. Common feeding practices may negatively affect feeding outcomes, such as providing too large of a bite of food or giving a child a texture that is too complex for current oral motor skills.

A review of current literature revealed that there is a need to support a healthy parent-child dyad to promote stability and development (Silverman et al., 2021). Parents of CWD report a need for community and belonging (Rabaey et al., 2021). When engaging in program development, a bioecological model provides a mechanism for addressing cultural and contextual barriers (Moramarco et al., 2018). Addressing PFD requires education of familial caregivers on postural stability as it impacts trunk control (Saavedra & Woollacott, 2015). Furthermore, it is wise to encourage caregivers to recognize the child's current ability and identify areas where the child may need more support.

Low literacy rates among the target population is a threat to knowledge translation. Consideration of teaching style and simplification of material will need to be considered when developing the program. To address this barrier, a multi-modal program that includes graphic illustrations, photography, verbal instruction, experiential learning opportunities for skill acquisition will be necessary.

Themes that emerged from the needs assessment included: 1) a need to equip partner organizations in LMIC with culturally relevant curriculum to translate knowledge of best feeding practices for CWD to parent to support family reintegration and promote family stability, 2) a need to support familial caregivers of CWD in LMIC through ongoing education and support in evidence-based approaches to evidence-based feeding practices, 3) a need to create culturally relevant supplemental educational materials to support knowledge translation (see Table 5 for SWOT analysis).

Table 5.

SWOT Analysis: Strengths, Weaknesses, Opportunities, Threats

Internal		External	
Strengths	Weaknesses	Opportunities	Threats
Count Me In to be utilized for data gathering, increasing knowledge base, and design model for future mobile development.	Lacks knowledge of CO-OP Model	Partnerships with technical experts. Tracey Smythe, PT	COVID-Public Health Crisis limiting ability to train community members
SPOON Inter-disciplinary staff	Lack of time to translate learning into a mobile format for parents	CE Opportunities to enhance and create a robust curriculum for parents	Literacy Rates
Access to CMMB	Need graphic illustrator	Similar programs have been develop using ToT	Language Barriers
Remote work is possible.	Mobile platforms require new architecture and coding.	ToT is well-researched and can inform current program development.	Parents limited understanding of development in children with disabilities
SPOON has used ToT and adult learning principles for Count Me In training.	Need to be aware of technical issues in country that could limit communication.	SPOON and WHO/Unicef have a graphics library that could be used.	Cultural beliefs or barriers that inhibit or impact ability to change
SPOON has strong relationships with partner staff in Zambia		CO-OP model can be expanded to parental training for co-occupations.	Prevailing beliefs about disability in the community

Conclusion

This needs assessment revealed a gap in service for familial caregiver education about PFD in LMIC. SPOON has an opportunity to fill a gap in service, through program development for knowledge translation utilizing a multi-modal bioecological model for the development of training curriculum. Three priorities were identified for program development with Zambia as the target country.

The first priority was to equip partner organizations in Lusaka, Zambia to translate knowledge of best feeding practice to community trainers to support family reintegration and stabilization. This priority was met by developing the FEED Safe Training Manual that incorporated the ToT model and adult learning theory. Potential barriers that were addressed included COVID-19 travel restrictions, understanding cultural context, developing a sustainable format for dissemination and utilization, and international communication.

The second priority issue was to train familial caregivers of CWD in Lusaka, Zambia in evidence-based feeding practices. This priority was addressed through the development of the FEED Safe Flipbook. community-based training model, and CO-OP model for training family caregivers in evidence-based feeding practices for children with disabilities in Zambia. The FEED Safe Flipbook was based on bioecological model and use the CO-OP model as a training tool to teach parents problem-solving skills (see Appendix B). Potential barriers that were addressed included overcoming knowledge translation when low literacy is a factor, language barriers, cultural beliefs or stigma that impede best practices (Nayar et al., 2014).

The third priority issue was to create supplemental FEED Safe handouts to support skill acquisition. FEED-Safe handouts would provide an illustrated depiction of best feeding practices to promote the use of skills in the home setting. Potential barriers that were addressed include acquisition and development of culturally applicable content, language barriers, and literacy barriers.

Chapter Four: Process and Product

Plan and Process

Program development of FEED Safe had three stages: discovery, development, and delivery. Goals for each stage were developed based on the results of the scoping review, stakeholder objectives, and global public health initiatives with the intention of promoting knowledge translation from academia to community to family caregivers of children with PFD in Zambia (see Table 6). A timeline of the project indicates the progression of the project over 14 weeks (see Appendix C). Excel was used to create Gantt chart for project management (see Appendix D).

Project status meetings were conducted weekly to ensure objectives were being met. Additional multi-disciplinary team meetings were conducted as necessary to ensure cultural and contextual viability of the product, discuss resource management, and end-user acceptance of the product. Data analysis was conducted over a four-day period and results were communicated with SPOON staff. Final recommendations for next steps were conveyed to SPOON staff. Recommendations are discussed in chapter six.

Table 6.

Program Development Goals and Objectives

	Objectives
Discover Goal: Improve knowledge of best practice in feeding children with disabilities to inform module content for caregivers in Zambia	1. Complete continuing education courses about the International Dysphagia Diet Standardisation Initiative to gain knowledge for content development. 2. Complete continuing education courses about training caregivers who have children with PFD to gain knowledge for content development. 3. Complete continuing education course about responsive feeding to gain knowledge for content development. 4. Complete continuing education course about infants with visual impairment to have knowledge for content development. 5. Throughout the project, discuss best practice with mentor, advisor, and multi-disciplinary team members to ensure content validity. 6. Interview stakeholders in Zambia to discuss current needs of families and factors that lead to institutionalization.
Development Goal: 1. Develop the FEED Safe Training Manual with content guided by bioecological model and using a ToT model. 2. Develop the FEED Safe Flipbook that incorporates the CO-OP model as a framework for overcoming barriers to feeding a child with PFD.	1. Document requirements from SPOON. Develop content strategy. 2. Develop content strategy for FEED Safe Trainer Manual and Feed Safe Flipbook. 3. Complete first draft of training materials and review with mentor. 4. Complete first draft of FEED Safe Handouts and review with mentor. 5. Complete second draft for review by multi-disciplinary team.
Delivery Goal: 1. Develop a survey to assess the final product for quality assurance and user acceptance. 2. Deliver the final product to SPOON for distribution to stakeholders in Zambia.	1. Complete a primary stakeholder review. 2. Assess product using a mixed-methods study. 3. Compile assessment data, report to stakeholders, and complete recommendations for next steps. 4. Deliver final product. Mail print version and upload all digital assets to SPOON database for future use.

Implementation

Setting and Participants

Work on this capstone project was completed in cooperation with SPOON based in Portland, Oregon and their CMMB partners in Lusaka, Zambia. All meetings were conducted remotely due to geographic barriers and travel restrictions due to COVID-19. Communication platforms were email, cloud-based survey services, and Zoom for video conferencing.

An inter-disciplinary team of stakeholders was established to: 1) identify gaps in services, 2) provide knowledge of best practices, cultural norms and standards, 3) edit and review program content throughout development. The interdisciplinary team consisted of occupational therapy, speech and language pathology, public health, human services, nutrition, technology, and physiotherapy. Stakeholders were identified based on professional knowledge, work with the target population, and availability. Two team members were partners in Lusaka, Zambia; two team members were from St. Catherine University in St. Paul, MN; and four team members were staff at SPOON based in Portland, OR.

Ethical approval for this project was received through the St. Catherine University Institutional Review Board and was categorized as quality improvement. The project did not include research with human subjects. All illustrations used in product development of this project followed copyright laws and were created for the sole use in the product or were previously created for SPOON for use and distribution. All photographs used in the curriculum have release forms on file with SPOON.

Project Components

The program development plan was categorized into three phases: discovery (4 weeks), development (8 weeks), and delivery (2 weeks) (see Appendix C). During discovery, cultural and contextual information was gathered from the stakeholder team and a review of evidence to inform the curriculum content. A strategy for development and project plan was completed. Stakeholder interviews

and surveys were conducted to identify gaps in knowledge among the target population (familial caregivers of CWD in Lusaka, Zambia). Literacy rate of the target population and aspects of language and word usage were investigated through research, surveys, and interdisciplinary team meetings. It was determined that FEED Safe would account for a low-literacy rate of caregiver population and a 10^{th} – 12^{th} grade literacy rate for trainers. Research of best practices in feeding children with disabilities was completed through literature review of scholarly articles, textbooks, and the completion of continuing education courses for responsive feeding practices, oral motor skill development, and the International Dysphagia Diet Standardisation Initiative rationale and framework, sensory skills and feeding, and visual impairment and feeding (Dilfer & Cohen, 2021; Dilfer & Cohen, 2020). Interviews and surveys were conducted to gain insight of cultural norms and contextual factors such as available resources, cultural feeding practices, and role delineation at mealtime within Zambian families.

After completing research on the target population, a strategy for knowledge translation of best practices in feeding children with disabilities was created. Research indicated that a community-based training model would be the most effective format for the target population. Bioecological model and dynamic systems theory would be used to develop a culturally appropriate curriculum and promote the use of local resources for sustainability of the program over time.

Stakeholders initially decided the FEED Safe training program would contain three training modules: Responsive Feeding, Safe Feeding, and Feeding Techniques. The fourth module on Nutrition was added during the development phase. The target audience was familial caregivers of CWD. Program design included a FEED Safe training manual for knowledge dissemination to community trainers. The training manual was written at a 10^{th} – 12^{th} grade level with definitions for new or clinical terminology. The creation of an illustrated FEED Safe Flipbook provided simplified language for trainers to communicate evidence-based practices in feeding to parents of CWD in the community. The estimated reading grade level for the flipbook was 7^{th} – 8^{th} grade for trainers. Family caregivers view images from

the FEED Safe flipbook and listen to the trainer explain concepts. Experiential learning activities were included throughout the four modules to promote skill acquisition. Supplemental handouts with simplified language and illustrations for parents promoted the generalization of skills into the home setting.

When developing a strategy for curriculum content, the topic ideas were put into a story board. The content was discussed between the author and the project mentor at SPOON. The decision to use a modular format provided flexibility for each individual to meet the needs of the target audience they were serving. The content was able to be delivered in multiple short sessions or one longer session.

A project plan was created in Excel using a Gantt Chart format to document discovery through review and was updated throughout the project to account for changes in scope and timeline. The project plan was approved by the writer's capstone advisor and mentor at SPOON who served as point-person on the project. Barriers to timeline adherence included delay in communication with international stakeholders, stakeholder vacations, and scheduling conflicts.

Throughout phase two, development, a dynamic systems and bioecological model were utilized to inform written content and illustrations. The FEED Safe training manual was guided by ToT theory. The FEED Safe training manual and FEED Safe Flipbook utilized adult learning principles which continues to be a preferred theory for ToT (CDC, 2019). The CO-OP model was introduced as a problem-solving strategy for parents under the title Goal, Plan, Do, Check (see Appendix B).

Figure 1.

Images from FEED Safe Flipbook.

Adobe Illustrator was used for designing culturally appropriate illustrations (see Figure 1). Adobe Photoshop was used for editing photography. SPOON provided access to their current illustration and photo library. Microsoft Word was utilized for word processing and layout of the product, Survey Monkey was used for survey distribution and data analysis, and Goodcalculators.com was used to check Flesch-Kincaid reading level throughout the project.

New vocabulary words that were above the preferred literacy level, such as *interoception* and *empathy*, were defined in simple terms and examples provided. The editorial team checked the manuscripts for language consistency, word choice, cultural appropriateness, and safety. The appropriate edits were made prior to delivery of product.

Phase three, delivery, included quality assurance and user acceptance. During quality assurance an interdisciplinary team reviewed the curriculum and provided feedback. The interdisciplinary team included original stakeholders and a parent of child with a PFD. Edits were made and the stakeholders received a final copy of the product.

Deliverables

SPOON received digital files for FEED Safe Trainers Manual, FEED Safe Flipbook, and ten caregiver handouts. In addition, they received digital files for over 75 illustrations and photographs for future use with signed release forms. A printed copy of a FEED Safe Trainer manual, a FEED Safe

Flipbook with easel-back, and caregiver handouts in a file folder were provided to SPOON Foundation upon delivery.

Deviations in Goals, Objectives, or Strategies

Goals and objectives for the capstone experience and project were met. Project timeline was adjusted due to availability of key stakeholders and all milestones were achieved on schedule. An additional module on nutrition was added to scope during the development phase. A deviation to the assessment plan was made due to public health and geographic constraints that prevented a focus group. Instead, a mixed-method survey was used to gather both quantitative and qualitative data. A single in-person interview was conducted with an adoptive mother of a child from Uganda who had PFD through early childhood.

Chapter Five: Evaluation and Results

Project Evaluation

The Quality Evaluation Assessment Tool (QUEST) from WFOT was used as a framework for product assessment and user acceptance (see Appendix D). Seven quality dimensions were analyzed including: appropriateness, sustainability, accessibility, efficiency, effectiveness, person centeredness, and safety. A cloud-based survey application was used to distribute a mixed-method survey to a multi-disciplinary team of key stakeholders (n=10) An interview was conducted with a parent of a child with PFD to gather qualitative data.

Results

Demographics of Survey Recipients

The review team of stakeholders consisted of professionals from: OT, SLP, PT, technology, public health, community health/human services providers, and an educator. One stakeholder resides in Zambia, six stakeholders reside in the US. Six stakeholders engage in international work, five stakeholders have completed work in Zambia.

Appropriateness

Appropriateness of the program would indicate that the right professionals would be able to deliver FEED Safe training at the appropriate time to the appropriate individuals. All of stakeholders believed the FEED Safe training manual would be effective at training community members (professionals, community-caregivers, etc.) in evidence-based approaches to feeding CWD. Stakeholders were asked to identify professionals in Lusaka, Zambia that would benefit from FEED Safe trainers training (see Figure 2).

Figure 2.

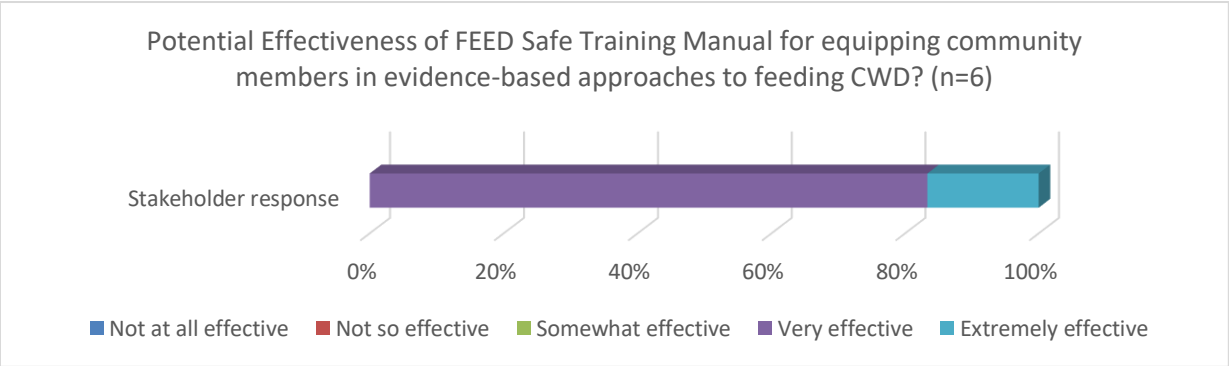


Figure 3.

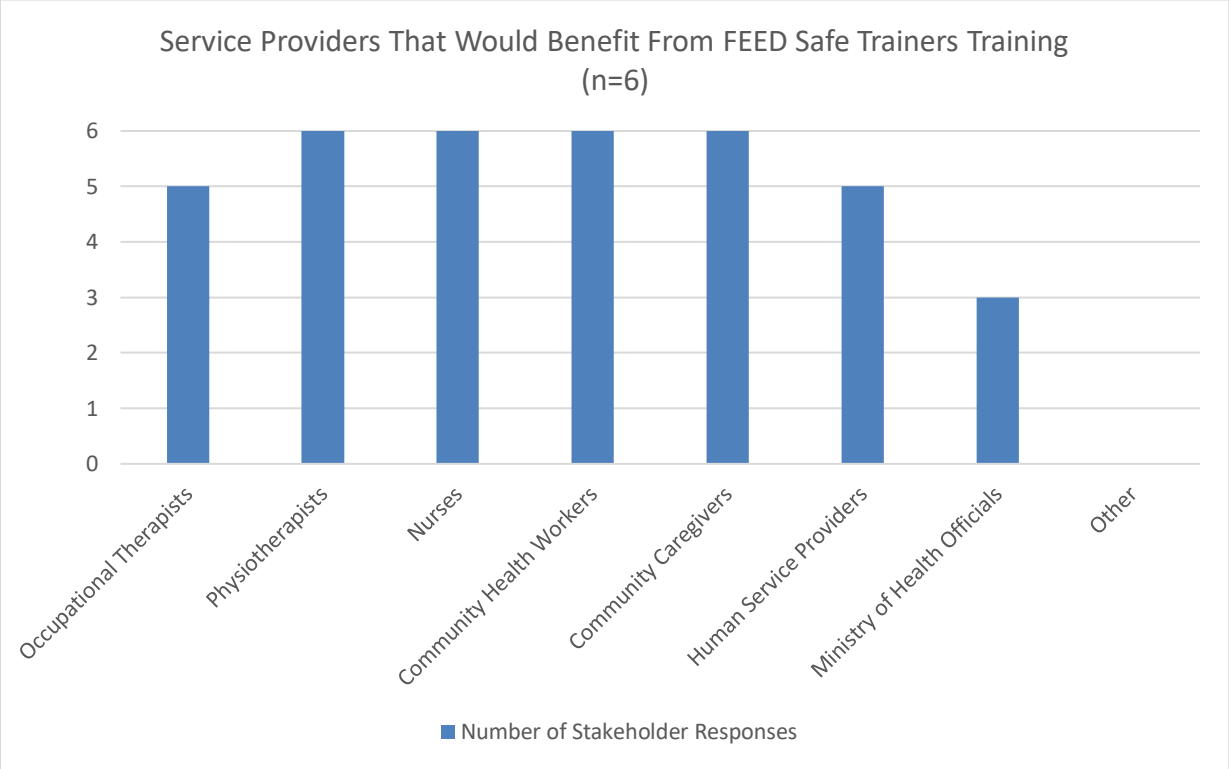


Table 7.

Ways the FEED Safe Flipbook Meets a Service Need for Training Family Caregivers in Evidence-Based Feeding Strategies (n=5)

Theme	Quote
Fills a resource gap	*"Fills a gap in our tools/materials for training family caregivers. Known need based on partner feedback in Zambia. Proves a resource outside of [current resources] that aligns with current project structure."*
	"One of the needs identified [by partner organizations] was a resource or tool to directly train caregivers about feeding and nutrition for children with disabilities."
	"In flipbook format is a unique format that makes training and parent education very "doable". In many LMIC there is a shortage of rehab professionals, and often there is not occupational therapy or others trained in feeding CWD. This training has evidence…"
Addresses low literacy	*"It is a simplified tool that even those who may not have high levels of literacy can easily speak into the pictures and share about their own practices."*
	"The flipbook provides the facilitator with a resource to disseminate simple messages…"
	"The clear instructions reinforce material from training manual, taught by trainers. The illustrations and photos clarify verbal instructions."
	"[FEED Safe] is broken down into understandable chunks of information."
Experiential Learning	*"The flipbook provides the facilitator with a resource [for family caregivers to] practice solutions."*

Sustainability

The sustainability of the program reflected the program's ability to use local resources to improve health outcomes without compromising current or future generations. It considers economic and environmental resources and agendas with the goal of improving empowerment and preventative interventions (WFOT, 2012). On a 5-point Likert Scale rating sustainability, with 0 being Not at all sustainable and 5 being extremely sustainable, 80% (n=5) of respondents reported that the print format of the curriculum was a 4-very sustainable. 80% (n=5) of respondents reported the supplies for training were commonly available in both urban and rural settings in Zambia. 20% (n=5) of respondents felt the

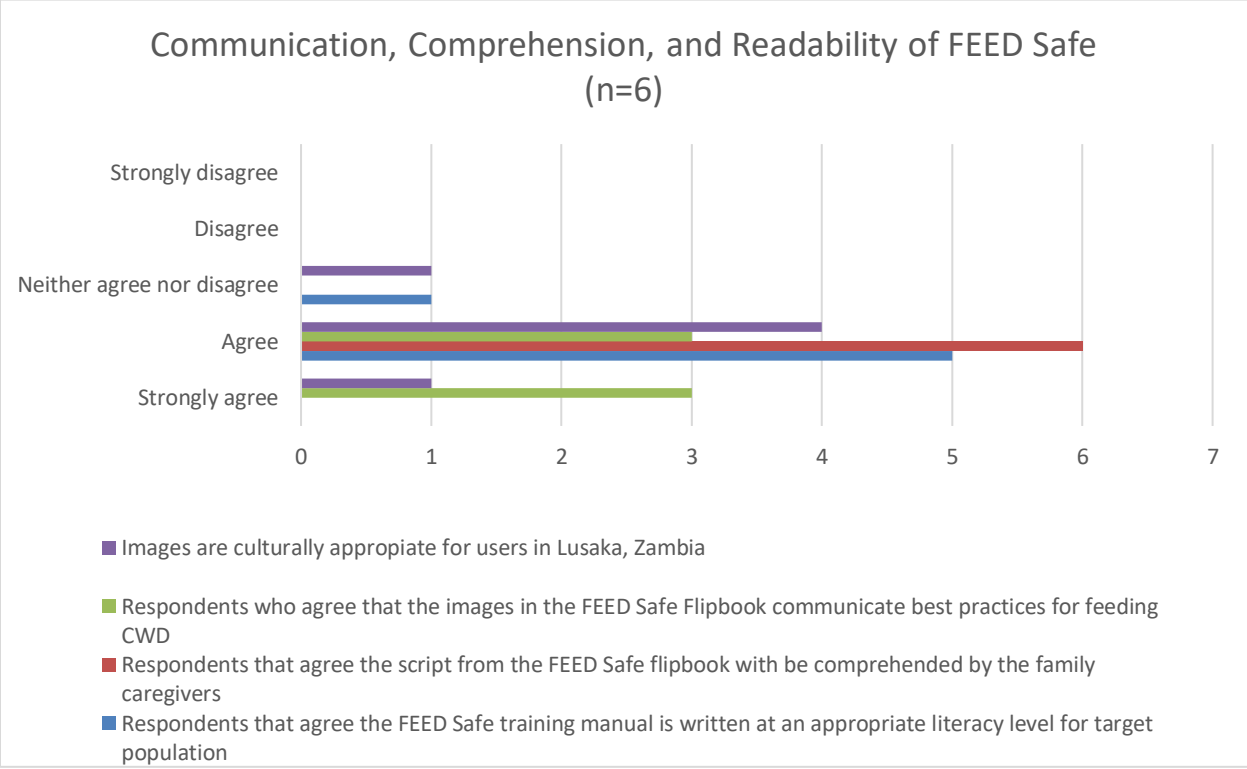
supplies were commonly available in urban settings only. One respondent reported that it may be difficult for families to find a sturdy plastic spoon to feed a child with a tonic bite reflex.

When considering technology for scaling and distribution into other markets, 71% of respondents thought the FEED Safe training program could be translated to a cloud-based program (n=7); 71% thought FEED Safe could be translated to video; and 85% thought FEED Safe could be made into a smart phone app. One respondent felt a progressive web app that was native to the device would be most beneficial because it could work offline, allow for interactivity, and flexible pacing. One respondent felt that FEED Safe could be integrated into existing programming (Count Me In).

Accessibility

The accessibility of the program considered the ease of knowledge translation from academia to local trainer to family caregiver. This measure considered the readability of FEED Safe for end users (trainers and familial caregivers) to assess potential comprehension of material. Respondents were also asked to assess the clarity of messages communicated via image. Images were also assessed for cultural appropriateness for users in Luska, Zambia (see Figure 4).

Figure 4.



Efficiency

The efficiency of the program considered the optimal use of resources to yield maximum benefits for program recipients. On a 5-point Likert Scale that rated efficiency from 0-not at all efficient to 5-extremely efficient, 83% of stakeholders (n=6) found FEED Safe to be 4-very efficient in using resources and 17% of stakeholders found FEED Safe to be 5-extremely efficient in using resources.

Effectiveness

The effectiveness of the program considered the ability of FEED Safe to achieve knowledge translation of evidence-based feeding practices to family caregivers in Lusaka, Zambia. Overall, the respondents felt that FEED Safe conveyed evidence-based techniques for many feeding challenges (see Table 8). Potential effectiveness of the ability of the FEED Safe Flipbook to train parents how to problem-solve using the CO-OP model was also measured. Respondents were asked to consider how the

FEED Safe training program teaches caregivers how to problem-solve feeding challenges (see Table 9). Measured on a 5-point Likert scale of 0-not at all effective to 5-extremely effective, 100% of respondents (n=5) thought the FEED Safe handouts would be a 4-very effective for promoting the use of new skills in the home by family caregivers.

Table 8.

Percent of Stakeholders who thought FEED Safe was Effective in Conveying Evidence-Based Techniques (n=6)

	Yes-FEED Safe is Effective	Partially-FEED Safe is partially effective	No-FEED Safe in not effective
Responsive feeding	100%	-	-
Positioning	100%	-	-
Modifying food textures	83%	17%	-
Identifying feeding distress	100%	-	-
Feeding a child with contractures	67%	33%	-
Improving lip closure	100%	-	-
Feeding a child with tongue thrust	100%	-	-
Clearing mouth of food	100%	-	-
Feeding a child with tonic bite reflex	83%	17%	-
Cup drinking	100%	-	-
Choosing foods for a CWD	67%	33%	-

Table 9.

Ways FEED Safe Training Teaches Caregivers to Problem-Solve Feeding Challenges

Theme	Respondent Quotes
Provides a problem-solving strategy	*"I like the integration of goal, plan, do, check…"* *"I like that [FEED Safe] introduces caregivers to a systematic approach to planning and for assessing a mealtime with goal, plan, do check."* *"The method of goal, plan, do, [check] is strong for teaching caregivers to observe and modify practices for best outcome."* *"The use of Goal-Plan-Do-Check is an easy cognitive strategy that can be taught and then monitored by professionals and CHW."*
Provides solutions through images	*"The pictorial depictions are also very helpful."*
Training covers many feeding challenges	*"[FEED Safe] provides solutions for at least each possible physical limitation for children with feeding difficulties."*
Allows caregivers to share experiences with one another	*"…[Feed Safe] provides space to discuss [caregiver's] own issues with feeding their children. Knowledge sharing is important."* *"…[Feed Safe] facilitates a discussion between the mother on their experiences."* *"Promotes discussion and practice by engaging caregivers."*

Person-Centeredness

Person-centeredness considered the program's ability to meet the needs of program recipients. For users in Lusaka, Zambia, it was important to design a culturally relevant training program. Skill acquisition and promoting the opportunity to build support groups are aspects of a person-centered training program (see Tables 10 and 11).

Figure 5.

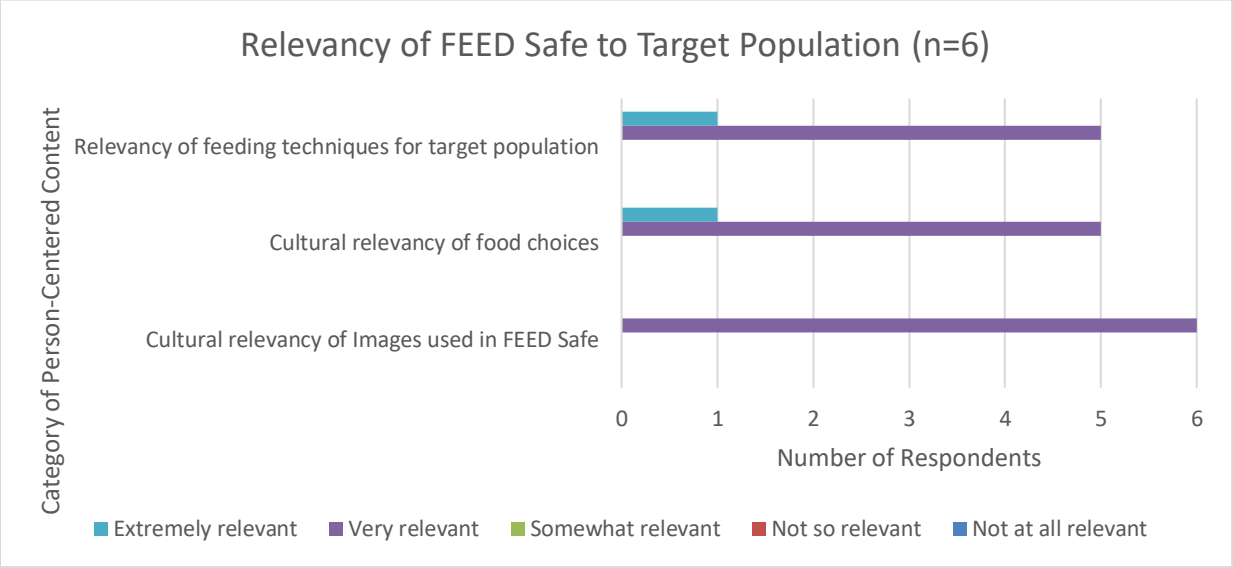


Table 10.

Ways FEED Safe could provide family caregivers opportunities to learn new feeding skills (n=6)

Theme	Respondent Quotes
Participatory	*"The program provides instruction followed by opportunities to practice new skills, then discuss their experiences."* *"It is participatory in nature in the sense that parents get to share their own experiences with feeding their children and get to ask the facilitator questions pertaining to challenges."* *"Feeding children with disabilities is a hard task and can be very complex. [FEED Safe] provides foundational skills for families to practice right away and get support and coaching."*
Addresses psychological barriers that impacts feeding	*"One of the strongest aspects, though, has to be the opportunity for caregivers to explore their feelings associated with caring for a child with disabilities and importance of connection with their child. We know that caregivers of CWD experience increased stress and caregiving burden as well as stigma and we also know that behavior change is more successful when we understand what motivates an individual. Creating a space for caregivers to feel heard may motivate positive changes in mealtime behaviors."*
FEED Safe handouts	*"The provision of the handouts has the potential to work as an incentive for more practice at home."* *"Through practice sessions and handouts to take home."*

Table 11.

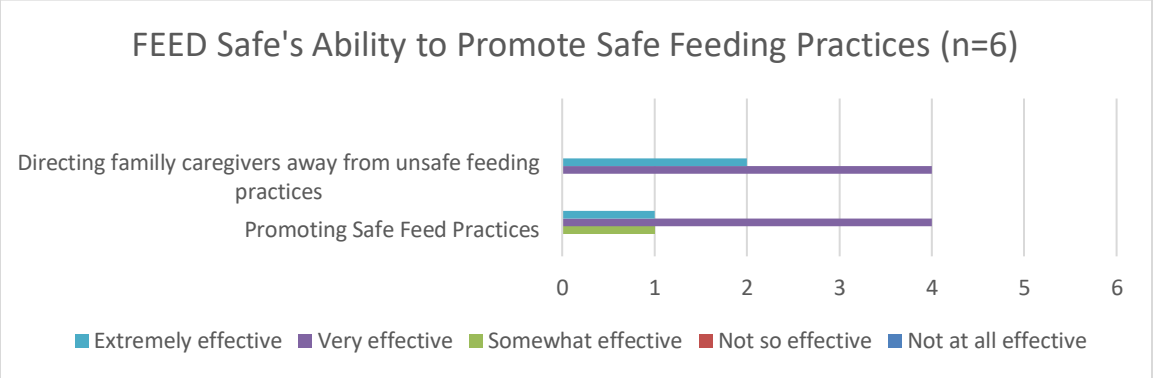
Ways FEED Safe could provide family caregivers opportunities to build a support team (n=6)

Theme	Respondent Quotes
Community-Based	*"Working with mothers from the same community gives them an opportunity to see their common challenges and find ways to support each other."* *"The training is designed in such a way that it is given in a group set-up, the gathering of caregivers with children having similar challenges can also be viewed as a peer to peer support group."* *"Using [FEED Safe] in a group format/setting would allow families to support each other and share things that have worked or not worked for them. Often parents with a child with a disability (especially in a LMIC) feel isolated and shunned."*
Participatory learning sessions	*"Learning and sharing with other caregivers about the challenges they face and the successes they experience creates a critical opportunity for connection, support, and community. This is especially important for caregivers of CWD who may experience stigma within their communities and families."*
Integration into existing programming	*"I can envision this being [used] in the Kusamala + play groups, and 1:1 sessions between CCGs and family caregivers. In play therapy they will be able to share knowledge and experiences with other family caregivers with similar experience."*

Safety

Safety considered the degree to which the program avoids harm and reduces risk to end-users. Ideally, FEED Safe would train family caregivers in evidence-based feeding techniques that promote safe feeding practices. On a 5-point Likert scale, users rated the effectiveness of FEED Safe to promote safe feeding practices and directing family caregivers away from unsafe feeding practices (see Figure 6). Sixty percent of respondents said that FEED Safe would be very effective at promoting safe feeding practices and 20% of respondents said that it would be very effective at promoting safe feeding practices. All respondents said that FEED Safe would be very effective or extremely effective at directing caregivers away from unsafe feeding practices.

Figure 6.



Parent Review

An in-person review of the FEED Safe Flipbook was conducted with an adoptive mother whose son from Uganda suffered from PFD in early childhood. The mother lives in rural Minnesota and must travel one-hour or more to reach the nearest children's specialty center for care. As a toddler, her son received OT for feeding and PT for strength and mobility. The child is now 12 years old. The author reviewed the four FEED Safe Flipbook modules with the mother over a 3-hour period and the mother provided feedback (see Table 12).

Table 12.

Parent Feedback from FEED Safe Flipbook and FEED Safe Handouts (n=1)

Theme	Quote
Validation	*"It's so critical that you addressed the feelings of the parent who is trying to get their child to eat. It's lifesaving and critically important. As a parent you feel desperate, hopeless, and helpless. Everyday you're trying to feed them and it's not working. Just to validate the parent's feelings builds trust between the trainer and the parent. Even reading this brings back all the feelings. It's so important to validate those feelings right away. It gives the parents hope. There is hope that someone can help them."*
	"I would have given myself more grace because I was so frustrated and then I felt guilty."
Skills Acquisition	*"Sensory stuff always has me a little baffled. I always thought about touch and smell, but I never thought about the texture of food going into the child's mouth. If I would have known that I would have changed how I fed my child…I never considered changing texture."*
	"I would change the texture of the food… I would try positioning him differently. I didn't know about position before. I knew that he was behind in walking but didn't realize that may affect his eating skills."
Responsive Feeding	*"Because of the texture piece you brought up, we were eating a meal and he had a chunk of chicken. Some of the chicken was dryer than other parts. He ate around the dry chunks. I told him he needed to eat the chicken, like I used to, then I realized it was the texture. So, I took the food away and didn't make him eat it and I gave him a different food and he had such relief on his face."*
Generalization of Skills	*"You can't remember everything you hear, so the handouts are critical. Then you have something to remind you and reference back to. The handouts would remind you of what was said in the training. I love lists and directions and I like that the handouts."*
Format of Class	*"I love the Flipbook. It's such an easy thing."* *"I think it is a great way for parents to share. You feel so alone when you have a child who has problems eating. To be able to share with other moms is so important."*
	"I wish I would have had this when he was little."

Chapter Six: Discussion and Impact

Discussion

The purpose of this doctoral capstone project was to develop an evidence-based feeding program to train familial caregivers of CWD in Lusaka, Zambia. Based on results from a scoping review, a dynamic systems theory and a bioecological model were used in the development of the program to ensure sustainable, evidence-based feeding strategies that would be culturally valid and accepted in LMIC (Aprilia & Soendari, 2018; McLinden et al. 2018). The approach harnessed knowledge by way of a multi-disciplinary team to provide a more comprehensive program. The ToT model and adult learning principles provided a framework for the development of the FEED Safe Training Manual to ensure knowledge translation from academia to community-based trainers (CDC, 2019). The synthesis of information from various fields such as OT, PT, public health, nutrition, and health and human services contributed to the creation of a holistic program. A community-based training model was used as the format for knowledge dissemination (Donkor et al., 2018; Zuurmond et al., 2018).

Program development of FEED Safe was completed within the projected timeframe and met the project objectives. The contributions from and assessment by a multi-disciplinary team ensured a holistic approach to training that was evidence-based across multiple allied health domains including: occupational therapy, physiotherapy, speech and language pathology, public health, nutrition, and health and human services. QUEST assessment of FEED Safe by a multi-disciplinary team of professionals revealed positive results in seven quality dimensions: accessibility, appropriateness, effectiveness, efficiency, person-centeredness, safety, and sustainability (WFOT, n.d.). Five themes emerged from qualitative data gathered from parent review of the curriculum: validation, a format that promotes skill acquisition, benefits of responsive feeding strategies, generalization of skills to the home setting, use of a class format that provides support in a community-based setting. Technical consideration of program

format, digital assets, and content provide the basis to consider scaling and distributions in various markets globally.

Strengths of the Project

FEED Safe Can Promotes Knowledge Translation. The use of a ToT model and adult learning principles promoted the dissemination of information from academia to community caregivers. Data from the QUEST assessment suggested that FEED Safe would be an effective and accepted program by the target audience in Lusaka, Zambia.

FEED Safe Can Empower Caregivers. The promotion of responsive feeding practices improved psychological and emotional health of caregiver and child. FEED Safe acknowledges the challenges of caregiving, thus validating the caregiver. Such validation may reduce stress and promote positive mental health. The utilization of evidence-based feeding strategies offered by physical and occupational therapists provide a caregiver with skills that have been shown to be effective with CWD. Furthermore, the experiential activities allow caregivers to acquire new skills and empowers them to care for their CWD in the home. Likewise, FEED Safe handouts used images from the course to promote generalization of skills in the home.

FEED Safe has Culturally Relevant Content. FEED Safe was created to address low literacy by using culturally appropriate images to communicate best practices in feeding strategies in the FEED Safe Flipbook. Using customized illustrations, photographs, and training examples the FEED Safe curriculum provides culturally relevant feeding training at an appropriate literacy level to meet the needs of the target population in Lusaka, Zambia.

FEED Safe Provides Opportunities for Caregivers to Build Support Networks. The use of a community-based training model provides a mechanism for the caregivers to develop a support team of local professionals and other caregivers. This format validates the caregivers experience and provides a space for caregivers to learn from one another.

FEED Safe is a Sustainable Intervention. FEED Safe was designed to be a sustainable intervention. The use of a multi-disciplinary, international team of professionals was key to identifying tools and resources for inclusion in the program. Understanding how FEED Safe could be integrated into current public health programs in Lusaka, Zambia was key to sustainability. The use of tools and resources commonly available to family caregivers was critical to the program's acceptance by key stakeholders.

Limitations of the Project

The COVID-19 pandemic resulted in restricted travel affecting the discovery and delivery stages of program development. To address this barrier, cloud-based technologies were used for gathering data. Video-calling was used to meet with stakeholders. Access to families of CWD in Zambia was prevented due to COVID-19 quarantines. Therefore, reports from key stakeholders and literature review were used to assess the needs of the end-user.

The assessment of FEED Safe revealed two specific weaknesses: the topic of contractures and choosing foods for children with disabilities. FEED Safe was developed as a starting point to educating families and further modules and more detailed training could be created to address complex medical issues. Partners should consider existing nutritional education programs and consider how FEED Safe can be modified or adapted to meet specific nutritional or meal planning needs based on each family's need.

Impact of the Project

Expanding Service Opportunities

FEED Safe was designed to fill a gap in service for SPOON and CMMB by providing feeding training for familial caregivers of CWD. FEED Safe's digital assets support program launch in Zambia and supply a framework for translation into other markets. Furthermore, FEED Safe may strengthen the

relationship between SPOON and international stakeholders by meeting community needs and using sustainable resources within country.

Validation of Caregiver

FEED Safe addresses caregiver burnout and contributes to stress reduction by equipping caregivers of CWD to overcome feeding challenges by using the CO-OP model strategy: Goal, Plan, Do, Check. Module 2 and Module 3 highlight feeding strategies that can easily be replicated by the caregiver, improving their self-efficacy to care for a CWD. Furthermore, by equipping familial caregivers in evidence-based feeding strategies, the FEED Safe program may contribute to the reintegration of CWD into family care.

Contribution to Global Target

Throughout program development of FEED Safe, the author was mindful of WHO's (2015) sustainable development goals for 2030. The use of a dynamic and bioecological approach provided a means of assessing the needs of the community at various ecological systems levels with the intention of: 1) promoting well-being and ensuring healthy lives for all people of all ages; 2) improving nutrition; and 3) reducing inequalities (United Nations, 2015). At the individual and microsystem level, FEED Safe works to equip familial caregivers with evidence-based feeding strategies contributes to the health and well-being of CWD. A caregiver of a CWD who learns feeding strategies and increasing knowledge of nutrition, may improve nutritional intake for the child and improve developmental outcomes. At the mesosystem level FEED Safe works toward the reduction of inequalities for CWD in low-resource settings by equipping community trainers in evidence-based feeding strategy. Through knowledge translation, FEED Safe can reduce stigma and inequalities that plague families of individuals with disabilities. At the exosystem level, more professionals can be trained in caring for CWD in a responsive and thoughtful way. Through the community-based education that FEED Safe offers, community leaders

can advocate for those with disabilities at the macrosystem level, thus changing beliefs and enacting policies that promotes developmental justice for CWD.

Additionally, FEED Safe was intended to contribute to the WFOT research goals through the development of an effective intervention for the co-occupation of feeding (WFOT, 2016). FEED Safe promotes evidence-base practice with the main goal of knowledge translation. Through a dynamic and bioecological approach, FEED Safe promotes sustainable intervention that is culturally relevant and aims to increase a child's participation in everyday life (WFOT, 2016).

Promotion of OT Models and Frameworks in Emerging Practice Areas and Public Health Partnerships

FEED Safe promotes the CO-OP model approach by using it as a mechanism for family caregivers to problem solve feeding challenges. The introduction of CO-OP in feeding interventions could provide an innovative new tool for parents of children with PFD. FEED Safe also promotes the use the QUEST tool by using quality dimensions to assess potential effectiveness of a program during program development (WFOT, n.d.). FEED Safe promotes the value of occupational therapy in public health partnerships through the use CO-OP and QUEST in multi-disciplinary emerging practice areas.

SPOON Foundation Feedback

Upon delivery of the project, SPOON Foundation staff expressed their gratitude for a well-developed program that could go straight into a pilot assessment without editing. Staff expressed how excited they were to have a program for family caregivers that meets a gap in service. SPOON was pleased with the culturally relevant graphics, the design of the program, and the use of culturally relevant material throughout the program. Staff was pleased with the integration of the CO-OP model for problem solving and the use of QUEST for the initial assessment. SPOON staff is considering using the QUEST tool for the pilot program assessment.

Next Steps for FEED Safe: Functional Eating EDucation

SPOON partners will be printing the curriculum in Zambia for an upcoming pilot program. SPOON's community partners will identify community members to pilot the FEED Safe ToT training. Once CHW and CCG have been trained, SPOON can initiate a pilot of the FEED Safe parent training. It was recommended that SPOON partners use the QUEST assessment tool to assess the pilot training. Based on the assessment from pilot training, the FEED Safe curriculum should be edited to ensure program efficacy for the target population.

The following recommendations were given to SPOON in consideration of moving FEED Safe into other markets after program efficacy has been established in the initial market:

- Establish sustainable sourcing for supplies
- Determine feasibility of scaling into other markets
- Define funding sources for scaling and distribution
- Establish in-country program officers in new markets that can assist with cultural edits
- Secure a graphic designer that can edit graphics for cultural relevancy per market needs
- Secure translators for program language translation for new markets
- Investigate feasibility of other platforms for global distribution of product
- Continue to assess the need for new modules to be added to FEED Safe based on the needs of the target audience.

Conclusion

The development of FEED Safe had positive feedback from primary and secondary stakeholders. The program filled a service gap for SPOON and CMMB in Lusaka, Zambia. The application of evidence-based theories, models, and frameworks contributed to the successful and comprehensive development of FEED Safe. The use of existing models and frameworks in

new ways is an innovative approach to developing programs that contribute to the attainment of global public health initiatives. There is ample opportunity for SPOON implement and assess FEED Safe in Zambia to consider scaling and distribution into other viable markets.

Chapter Seven: Conclusion and Reflection

AOTA Vision 2025

FEED Safe: Functional Eating EDucation aligns with the AOTA Vision 2025 by providing an effective, accessible feeding training program that develops community leaders that will promote health equity for CWD in low-resourced communities. The development of materials that address low-literacy provides an equitable solution to caregiver education. Trainers of FEED Safe are comprised of existing community members of various disciplines. The ToT model provides a sustainable mechanism for effective and accessible training.

FEED Safe contributes to AOTA Vision 2025 through the use of evidence-based techniques to reduce feeding challenges for the CWD. Responsive feeding, positioning, and techniques for feeding challenges are backed by research and promoted widely across discipline. Through the utilization of adult learning principles and evidence-based theories, FEED Safe is a mechanism for knowledge translation. Ultimately, it is CWD and their families who will benefit from improved health and well-being.

Moreover, FEED Safe's collaborative approach aligns with AOTA Vision 2025 and promotes the value of OT leadership in public health partnerships. SPOON Foundation and partners have an opportunity to use FEED Safe to promote the value of CWD and reduce stigma surrounding disability in target markets. In doing so, they position themselves as community advocates and increase their potential to affect policy change in target markets.

St. Catherine Henrietta Schmoll School of Health

The FEED Safe program reflects the mission of the Henrietta Schmoll School of Health by engaging community partners to influence health outcomes within marginalized communities. The public health partnership with SPOON and CMMB furnished a multi-disciplinary team for a stakeholder

needs assessment and product review. This collaboration allowed for a dynamic and bioecological approach to develop such a comprehensive curriculum. The collaboration also created an avenue for the distribution of the FEED Safe program in Zambia and other markets. Digital assets can be easily edited to create culturally relevant content for target populations globally. With ongoing collaborations, FEED Safe could reach millions of families who care for children with PFD.

Moreover, FEED Safe also promotes the value of every life, a common principle in Catholic Social Teachings and the Henrietta Schmoll School of Health. Through responsive feeding strategies, CHW, CCG, and family caregivers of CWD are taught to see the value of each child and respect how that child experiences life. This evidential approach is founded in love, promotes positive relationships between caregiver and child, and contributes to reducing the stigma of disabilities in LMIC.

St. Catherine University Department of Occupational Therapy

This doctoral capstone project contributed to the St. Catherine University Department of Occupational Therapy mission by promoting OT theories, models, and interventions in emerging practice areas. Using the CO-OP model as a means to improve co-occupational performance and promote improved health outcomes serves a broader community. The FEED Safe program respects the dignity of the caregiver by validating one's lived experience as a caregiver for a CWD.

FEED Safe contributes to margin in a caregiver's life. When feeding time is efficient and safe, a family caregiver will have increased occupational balance. This may improve a caregiver's ability to manage their household, engage in fiscal endeavors, or connect in social relationships with others in their community.

FEED Safe has spiritual value in that it was designed to highlight the value of the lives of children who have developmental and feeding challenges. FEED Safe is an approach to health care that goes beyond humanism and scientific endeavor and embraces the spiritual connection between the child and

the caregiver. Responsive feeding is an approach that not only highlights the intrinsic value of a human life (humanism) but seeks to connect child and caregiver through the spirit of love and responsiveness.

SPOON Foundation

This capstone project contributed to SPOON's vision of a world where all children are valued and nourished. FEED Safe can provide family caregivers in low-resource settings knowledge and skills to improve safe feeding practices for their children. The development of FEED Safe improves cross-cultural partnerships by meeting a gap in service and enables partner organizations to equip community members with evidence-based approaches to feeding. FEED Safe can easily be integrated with other public health initiatives such as Kusamala + (a partnership between CMMB Zambia and a St. Catherine University interprofessional team).

Professional Development

This capstone project supplied ample opportunity for professional development and growth. As a result of this capstone experience, I improved my program development skills for occupational and public health initiatives. I improved my written communication for knowledge translation across cultures and contexts. I engaged in interdisciplinary collaboration for program development to improve pediatric health globally.

The development of FEED Safe required me to utilize tools from my doctoral courses such as Community Toolbox, WFOT's QUEST: Quality Evaluation Strategy Tool, and Excel's Gantt chart. The opportunity to utilize tools, strategies, model, and theories that I learned about provided me with real-world skills and tools that I can apply to organizations I serve in the future. The application of these tools also provided me with the ability to design new OT programs and interventions that can improve occupational performance of the populations that I am called to serve.

Throughout the capstone experience I also improved written communication for knowledge translation across cultures. The development of the FEED Safe program used UK English, which required attention to detail and the utilization of software to check spelling and grammar. I also was able to utilize analytical skills to derive an appropriate literacy rate for the target audience. The assessment of readability throughout development was a critical aspect of ensuring knowledge translation to the target population. Furthermore, the investigation of cultural practices and norms provided a cultural framework for content development. In turn, culturally appropriate content can contribute to the acceptance of the program by the end user.

The capstone experience required cross-cultural and interdisciplinary collaboration. This aspect of the capstone project improved my understanding of the scope of practice of other allied health and human service providers in both the US and Zambia. Team members were able to share educational, governmental, and professional resources that increased my knowledge. Moreover, it provided creative space to consider future projects and interventions that will improve the lives of children and families.

Overall, the partnership with SPOON and CMMB to develop FEED Safe: Functional Eating Education was key to a successful capstone experience and the development of a product that has the potential to impact the lives of thousands of CWD and their families. I look forward to a continued partnership with SPOON as they pilot the program in Zambia. Finally, as I move from student to practitioner, I look forward to collaborating with parents using interventions, such as responsive feeding, that promote attachment and build healthy relationships between parent and child to improve occupational performance of the family.

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Appendix A

Table A1.

Primary Stakeholder Interview Questions: SPOON

Topic	Questions
Organizational questions	Does SPOON aim to meet any of the UN Sustainable Development Goals for health equity?
	What are SPOON's current organizational goals that relate to educating caregivers?
	What conditions/diseases/disorders impact children served by SPOON?
	Can you tell me about the staff in partner organizations?
	Would I be able to interview overseas partners via email?
	Who are the caregivers/providers for the children with PFD in Zambia, Vietnam, Belarus, Uganda, Haiti, Tanzania, Oregon Foster Care System?
	What level of training do they have in PFD?
Barriers to knowledge translation and feeding success	What clinical barriers do children face in improving feeding?
	What are the geographical barriers in partner organizations?
	What are the demographic and social barriers your organization faces when educating caregivers?
	What are cultural barriers?
	Political barriers?
	Technological barriers? (access to certain types of food?, access to internet?)
Stakeholders	Who are primary and secondary stakeholders?
models and frameworks utilized for training	Are there any models or frameworks that are guiding your development of educational materials?
	Have you used group in-person training (for parents, institutional caregivers, medical personnel)?
	How has the Coronavirus Pandemic impacted the delivery of your training/education?
	How important do you think a multi-modal approach to training/educating is for the populations you serve?
	How important is a community-based approach to training/educating is for the populations you serve?
	How important is an online community for education or support?
	How important is a multi-disciplinary approach to training/educating is for the populations you serve?
Current and previous training/interventions	What interventions or training programs have been most successful thus far?

Table A2.

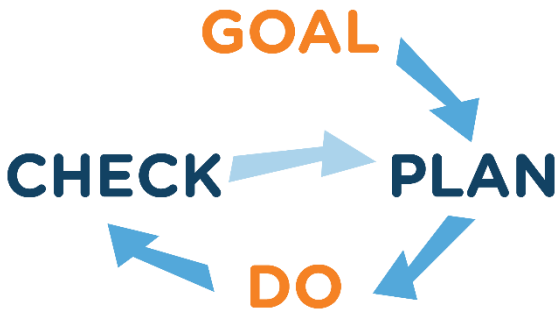
Primary Stakeholder Interview Questions: Technical Discovery

Topic	Questions
Platforms	What possible platforms would support an application for caregivers in LMIC to learn best feeding practices for their CWD?
Feasibility	How would content be managed and updated within an application? What types of media could we use to deliver content effectively in LMIC? How much effort, time, and investment would it take to build a mobile app or web app? What are the limitations that would need to be considered for use in LMIC?

Appendix B

Figure A1.

Cognitive Orientation to Occupational Performance (CO-OP) Model Use in FEED Safe



Excerpt from FEED Safe Training Manual (Fairchild, 2021):

Step One: Identify your GOAL

Before beginning a task, the caregiver will think about the GOAL. The caregiver identifies what they want to accomplish. Examples of a goal include: helping the child to eat enough food, helping the child swallow safely, or helping the child to learn how to drink from a cup. By identifying the goal, the caregiver has an idea of what they want to accomplish.

Step Two: Make a PLAN

After identifying the goal, the caregiver creates a PLAN. When planning the caregiver can think about the needed tools or supplies. Questions a caregiver may ask themselves when creating a plan include: What food will I prepare? How will I position my child? Will I sit on the floor or in a chair when feeding my child? How much time will I set aside for feeding my child? How will I keep my other children occupied while feeding their sibling?

Step Three: DO the task

Once the caregiver has created a plan, the caregiver will assist the child and DO the task as created in the plan.

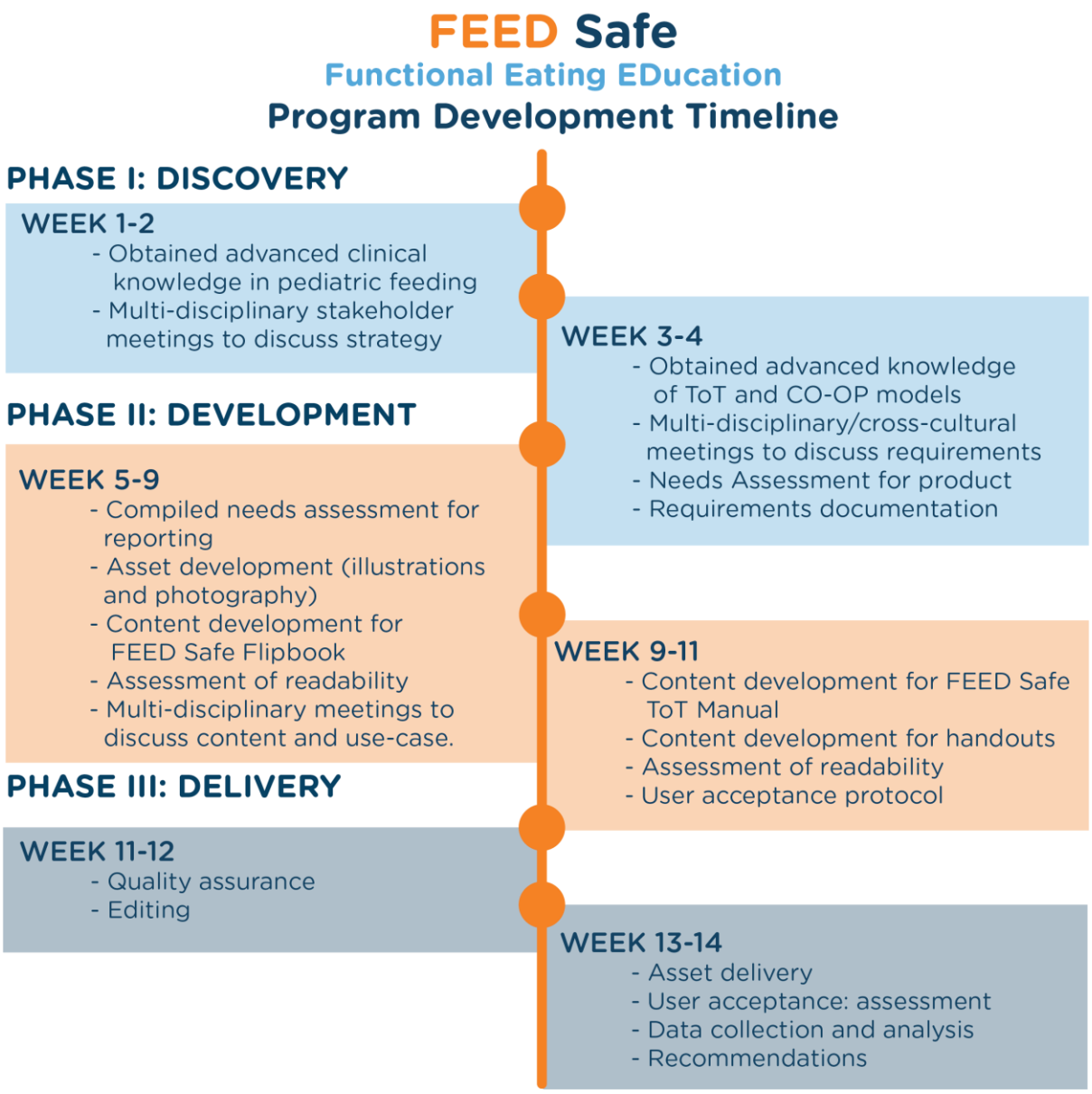
Step Four: CHECK your outcome

Caregivers will CHECK their progress as they do their plan. They may notice what is going well and what is not. If things are going well, the caregivers continue with the plan. If something is not working, instruct caregivers to go back to the planning stage and consider what they may do differently. The caregivers can ask, “What can I change to make this a better experience?”. Caregivers may go through the plan, do, check stages multiple times to make feeding safe and efficient.

Appendix C

Figure A2.

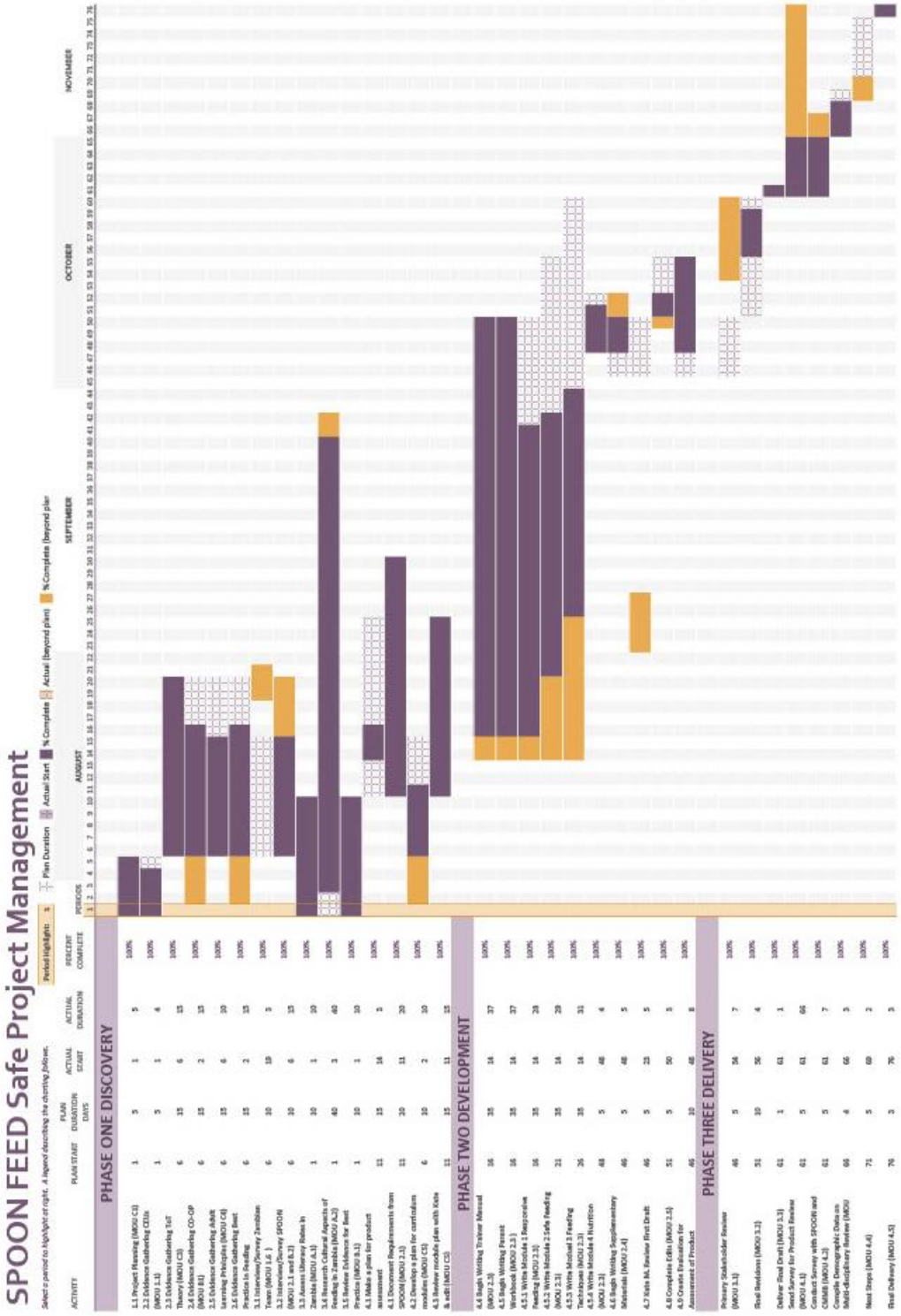
Program Development Timeline



Appendix D

Figure A3.

Gantt Chart: Project Plan



Appendix E

Table A3.

Survey Questions

Demographic information of respondents.	Place of employment. What is your profession or title? Country of Residence. In what country or countries do you work?
Appropriateness: The availability of the right professionals to deliver the program at the right time.	How effective do you think the FEED Safe Training Manual will be at training community members in evidenced-based approaches to feeding children with disabilities? In what ways does the FEED Safe Flipbook meet a service need for training family caregivers in evidenced-based approaches to feeding children with disabilities? Check the following service providers in Lusaka, Zambia that would benefit from FEED Safe ToT manual: Occupational therapists, physiotherapists, nurses, community health workers, community caregivers, human service providers, ministry of health officials, other
Sustainability: The program's ability to use local resources to improve health outcomes without compromising future generations.	How sustainable is the print format of the curriculum? How available are the supplies listed in the FEED Safe Flipbook? What other platforms could you translate the content for scaling and distribution?
Accessibility: Ease of knowledge translation from academia to local trainer to family caregiver.	Do you agree with the following statement: The content of FEED Safe Training Manual is written at an appropriate literacy level for potential trainers? Do you agree with the following statement: Family caregivers will comprehend the script from the FEED Safe Flipbook that is read by the trainers. Do you agree with the following statement: The images in the FEED Safe Flipbook communicate best practices for feeding children with disabilities. Do you agree with the following statement: The images in the FEED Safe Flipbook are culturally appropriate for users in Lusaka, Zambia.
Efficiency: The optimal use of resources for maximum benefit.	How efficient is the FEED Safe training program in using local resources to optimize knowledge translation (sharing best practices in feeding from professionals to families)?
Effectiveness: The program's ability to achieve knowledge translation.	Does FEED Safe Convey evidenced based techniques for: responsive feeding, positioning, modifying food textures, identifying feeding distress, feeding a child with contractures, improving lip closure, feeding a child with tongue thrust, clearing mouth of food, feeding a child with a tonic bite reflex, cup drinking, choosing foods for a child with a disability? In what ways does the FEED Safe training program teach caregivers to solve feeding challenges?
Person-Centeredness: The program's ability to meet the needs of program recipients	How effective do you think the FEED Safe handouts will be for promoting the use of new skills in the home by family caregivers? How culturally relevant are the illustrations and photos used in the FEED Safe program? How culturally relevant are the food choices in the FOOD Safe program? How relevant are the feeding techniques for children you serve (lip and jaw support, safe positioning for contractures, cut-out cup, reducing tongue thrust, and learning to chew)? In what ways do you think the FEED Safe program provides family caregivers an opportunity to learn new skills? In what ways do you think the FEED Safe program provides family caregivers an opportunity to build relationships or a support team with other caregivers?
Safety: The degree to which the program avoids harm and reduces risk to end-user.	How effective is the FEED Safe program at promoting safe-feeding practices? How effective is the FEED Safe program at directing family caregivers away from unsafe feeding practices?