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Service design to assist caregivers of adults with learning disabilities

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ABSTRACT

This project investigated a design solution to assist the caregivers of adults with learning disabilities (McRae et al.) in Thailand. The problems associated with LDs are increasing annually. The bulk of primary caregivers are individual family members who provide caregiving services without sufficient support from healthcare organisations. The challenge to Thai caregivers is to maintain their career while concurrently providing care to people with LDs. In some instances, they are pressured into quitting their jobs to care for family members with LDs. This research project employed a design thinking methodology, which is a qualitative approach. Based on trial-and-error attempts and proactive practical experience using the design thinking process, this research established that design outcomes must rapidly meet user needs through the product development cycle of prototype and testing. The results of this research offer a service design solution that can be used to provide support groups for caregivers. The design applies a token system (time-based currency) as a medium for group members with which to either provide or acquire caregiving advice and support they support others in the same position by providing caregiving services on a rotational basics. These services also provide a venue for caregivers through which they can stay connected while also serving as a learning environment.

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ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

25/09/2020

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I am extremely grateful to my family, particularly my mother, who is the real fighter, and to my cousins, who took care of my mother while I pursued a master's degree, my father and my lovely brother, who inspired me to work on this research topic. You are all the light that never fails to guide me when I feel lost. Without all of your support, this research would not have been possible.

Finally, I would like to commend myself for metaphorically getting back up every time I fell down on what has been a long and arduous but purposeful journey.

ETHICS APPROVAL

Ethical approval was obtained from the Auckland University of Technology Ethics Committee (AUTEC) on 4 December 2019 (AUTEC reference number, 19/397).

INTRODUCTION

RESEARCH RATIONALE AND BACKGROUND

Typically, most adults with a learning disability (LD) are maintained at home (Stevens, 2004). In Thailand, individual families will typically provide caregiving services, with less support from healthcare organisations. This research investigated the problems associated with such caregiving within a Thai family. The learning-disabled population is increasing annually (Plubrukarn, Piyasil, Moungnoi, Tanprasert, & Chutchawalitsakul, 2005), presenting a critical problem in the Thailand context.

The researcher first gained practical experience as a caregiver to her brother with an LD. She became passionate about creating a service specifically designed to assist caregivers in the same situation as a means to enable those with LDs to lead better lives and to raise public awareness of the problem.

RESEARCH OBJECTIVE

The primary goal of this study was to achieve an in-depth understanding of the problems that Thai caregivers deal with when caring for learning-disabled family members. The aim was to develop service design in a way that would enable it to suitably and effectively help the family caregivers of those with LDs to deal with challenges that may arise.

This research delineates three different challenge layers, i.e. religious and cultural background, community challenges, and individual challenges. Interviews were conducted to gain an understanding of participants through real bottom-up voices of customers, and the design was tested by users.

RESEARCH GAP AND RESEARCH CONTRIBUTION

The existing literature raises issues associated with the caregivers of learning-disabled people, particularly in terms of challenges and coping strategies of providing care for LDs and receiving care for themself. However, only a small percentage of the research focuses on the individual challenges experienced by family caregivers. Accordingly, this research contributes to a more comprehensive understanding of the Thai context in this regard. It unpacks insight related to Thai family caregivers as a means to address the research gap and the challenges experienced by participants by applying a design thinking process.

RESEARCH METHODOLOGY

The research employs a design thinking methodology to unpack user insights. Design thinking tools were used to develop empathy with the target users. The primary aspects of the research method are as follows:

- Contextual review
- Online interviews
- Thematic analysis
- Persona

- Customer journey
- Problem statement
- Prototype and testing

RESEARCH QUESTIONS

1. How might a service be designed to assist the caregivers of adults with LDs in Thailand?

2. What are the key challenges that the caregivers of family members with LDs face in Thailand?

3. What design solutions can help improve/enhance the lives and experiences of caregivers so that they can better support family members with LDs in Thailand?

CONTEXTUAL REVIEW
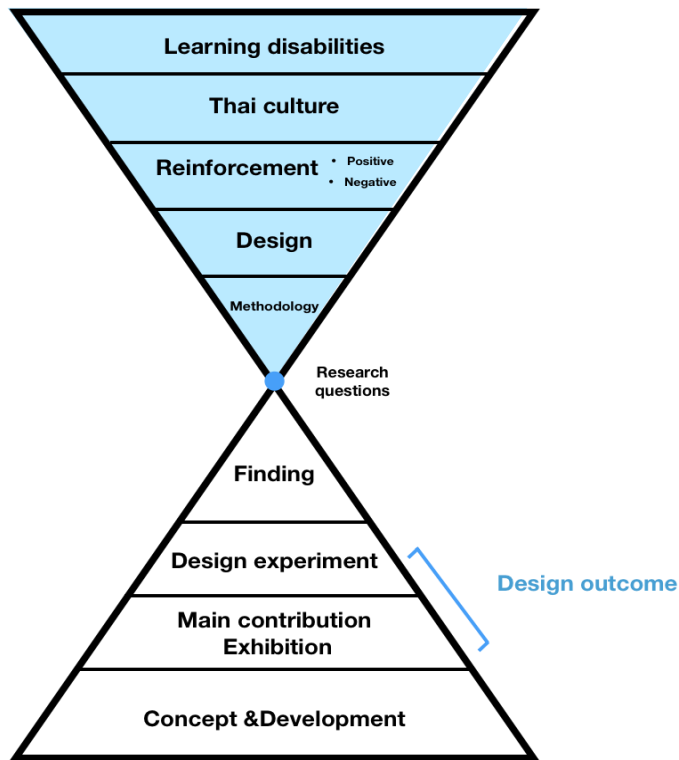
The research aimed to investigate the challenges that Thai caregivers experience in their daily lives while providing non-paid caregiving services. This section explores the context of the research question, 'What are the tools/services that can assist the relatives of Thai people with LDs or family members who act as their caregiver at home?' The researcher was inspired by her personal experience as the sister of an autistic brother. Her approach to caring began by gaining an understanding of the target user's background and identifying problems within the caregiving ecosystem. This project focused on the caregivers of people with LDs in Thailand (see figure 1).

The purpose of this research was to better understand the challenges Thai caregivers face and, accordingly, design a solution that addresses one of their key challenges.

The contextual review is divided into four sections as follows:

1. Target user – the caregivers of people with LDs and their living conditions.
2. Location – Thailand and Thai culture, which influences caregiving in Thailand.
3. Applied theory – the coping strategies (positive reinforcement and other motivations that can be implemented in providing care to people with LDs at home.)
4. Market research – existing product and service designs.

TARGET USER – CAREGIVERS OF ADULTS WITH A LEARNING DISABILITY

This research focuses on Thai caregivers who provide long-term caregiving to a family member with an LD. The researcher explores the process of providing care to adults with LDs. Compared with an average individual of the same age, a person with an LD does not live independently and, in most instances, are obliged to remain at home. The majority of people with LDs require caregivers to support them throughout their entire lives (Chapman, Lacey, & Jervis, 2018). Alfakhri et al.'s (2018) study of caregivers of dementia patients found that caregivers experienced problems associated with depression, feelings of being burdened, and a lower level of health-related quality of life. However, different health issues may be involved for caregivers of people with LDs. To date, limited research has been conducted on caregiving for people with LDs.

The initial step is to understand LD syndrome and the living conditions of those affected by it. 'Learning disability'[1] is defined as a disorder impacting one or more of the basic psychological processes of learning (Siegel & S., 2016). Learning disability is a subset of the autism spectrum (O'Brien & Pearson, 2004). Autism spectrum disorder (ASD) includes a variety of syndromes that can range from a single to multiple syndromes. The use of the classification 'spectrum' denotes the difficulty of classifying this condition, similar to describing the nature of light within a spectrum (Rudy, 2018). According to an existing study (Grant, Ramcharan, Flynn, & Richardson, 2010), LD individuals commonly exhibit problems related to mathematics and language.

Learning disabled people exhibit a variety of symptoms that are collectively referred to as the 'LD spectrum'. The six common symptoms commonly found in individuals with LDs include dyscalculia (general mathematical disability), dysgraphia (writing difficulties, typically linked to brain trauma), dyspraxia (motor skills problems and poor hand-eye coordination), dyslexia (reading disorder), attention difficulties hyperactivity disorder (ADHD), and Gerstmann's syndrome (a rare neurological disorder that induces the loss of four specific neurological functions, i.e. an inability to write, the loss of the ability to do mathematics, the inability to identify one's own fingers (or those of others). (Grant et al., 2010 & Richardson, 2010).

An LD person commonly has overlapping syndromes with autism as it relates to communication and social skills, which can include repetitive behaviours and obsessive behaviour linked to specific

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[1] In this research, 'learning disability' refers to the international ICD-10/DSM-IV term 'mental retardation'.

things. For example, Sam Gardner, the main character in the television series *Atypical*, is a teen with autism who obsesses about penguins. He visits the museum weekly and each time systematically performs the same activities.

In the current study, the researcher included caregivers caring for those with autism and more general learning disabilities'. The researcher also separated people with LDs into two groups, i.e. high-functioning autism (HFA) and low-function autism (Alfakhri et al.)sets (Alfakhri et al., 2018) (Gorsuwan & viriyanggul, 2019). Lotspeich et al. (2004) determined autism using an intelligence quotation (APA) test, with a low-functioning autism IQ indicated as a score lower than 70 (LFA; IQ < 70), and a high-functioning autism IQ higher than or equal to a score of 70 (HFA; IQ ≥ 70). 'High-functioning autism' refers to an autistic person who can read, communicate, and take care of themselves in everyday life. This group still requires a degree of support from others, but are better equipped to lead an independent life compared with the low-functioning group (Rudy, 2018). Low-functioning autism is identified by physically different body and facial characteristics. This group requires intensive care from caregivers, as they are less able to care for themselves and lack communication skills compared with the higher-functioning group. The researcher derived an intersection of the needs of participants in both groups and designed a potential design outcome for them (see Table 2).

THE IMPACT OF THAI CULTURE AND BUDDHISM ON CAREGIVERS

The challenge for Thai caregivers is that people in Thailand are generally unaware of LDs, despite it being a growing issue. The number of people with LDs increased from 1998 to 2002 yet remained a hidden issue in Thai society. A study in 2002 showed a growing number of new autistic spectrum disorder cases among children and adolescents who attended the Queen Sirikit National Institute of Child Health Clinic (QSNICH) in Thailand (Plubrukarn et al., 2005). Fulk, Swerdlik and Kosuwan (2002) stated a lack of public and private caregiving service organisations in Thailand as contributing to the difficulties experienced by Thai family caregivers. The Arunothai organisation for special needs persons was one of the private services contacted by the researcher. However, engagement with the organisation decreased following the death of its founder's son, which serves as an example of the lack of software support and service system it was needed to help organisation keep engagement with other members.

Buddhist caregivers believe that past deeds in a previous life caused patients' current disabilities, while their own past lives dictated them to be caregivers (Subgranon & Lund, 2000). This is based on

caregivers' acceptance of the law of karma, based on their Buddhist beliefs. Subgranon and Lund (2000) explained in their research that Buddhism's influence on family members played a significant role in providing care for their disabled relatives. Among these individuals, family members assuming full caregiving responsibilities is more common compared with accessing professional nursing in Thai culture. Additionally, Thai social norms dictate their need to do so.

This research focuses on the challenges and activities experienced at an individual level. Thai society and culture play a part by informing caregiver's experience; however, this is not the primary focus of the design outcome. The next section explores existing coping strategies that caregivers employ for providing home-based care to better understand the gaps and opportunities for a potential design outcome.

CAREGIVER COPING STRATEGIES

This section explores the current coping strategies that caregivers use when caring for a person with LDs, e.g. in a teaching situation, when providing medical treatment, and managing household tasks.

Studies on personal learning development in autistic education showed that positive reinforcement was widely used by professional nurses caring for a person with an LD (Ferster, 1964; McKenzie et al., 2018). Moreover, Clark (1996) noted that rewards and tokens were commonly used in households, with positive and negative reinforcement techniques adapted from parental care for normal children. Clark provides suggestions for how to manage negative behaviours away from home, such as using points, tokens, and contracts, and imposing 'time-outs', or using this approach on a particular toy. These tips can be useful when parents are faced with a specific situation, e.g. by rewarding tokens to teach children good behaviour.

A research study indicated the benefits of using a token economy in both professional and home caregiving. Weinschenk (2011) discussed stimulating behavioural changes by turning a long process into systematic smaller, motivating steps. Points and rewards were used to achieve a long-term goal (i.e. development of behaviour) by systematically collecting points. By conducting online interviews, the researcher studied how caregivers used these strategies to deal with daily challenges in home-care situations.

Negative reinforcement strategies (e.g. punishment and time-outs) are necessary tools for implementation in caregiving. Clark (1996) provides suggestions for how to handle aggressive and

dangerous behaviours. More importantly, using negative reinforcement can also enable parents to help children express their feelings. It seems that the key to using negative reinforcement is to combine reward and punishment strategies. The researcher will explore both of these strategies by posing questions to the research participants (refer to Appendix 2).

MARKET RESEARCH: PREVIOUS DESIGNS AND POTENTIAL REMAINING GAPS

The relevant market research was broader in scope than the current target group, which included the caregivers of people with LDs. The researcher explored existing design products that have been used in parental caregiving processes, as well as in caregiving provided to patients who had a long-term disease (e.g. diabetes) and design products aimed at seniors using caregiving services. The researcher aims to explore the caregivers of those with LDs as target users and will focus on a design outcome for them. However, the design outcome may also potentially benefit a broader population.

The research on existing products found two different types of products, i.e. digital applications (apps) and physical products.

Table 1: Market research conducted for caregiving physical product and digital Apps.
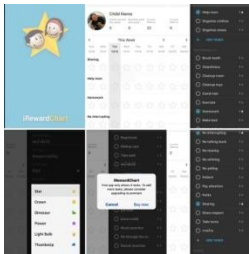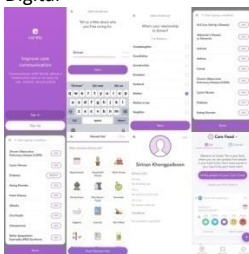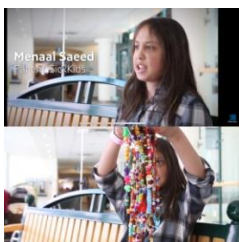
Name	Digital/physical	Pros	Cons	Gaps
iReward App for providing tokens between parents and children	Digital apps 	• Tokens and reward graphics were clear and easy to understand • User interface (UI) design suitable for use by a parent	• Too much text • Not suitable for those with LDs • Not easy to modify/daily additions are cumbersome • Complicated UI design	• A 'token' graphic/a 'token' (nominal) reward may cause anxiety for a person with an LD
Carely App for caregivers who take care of patients in medical therapy, e.g. diabetics	Digital 	• Good for psychiatric medical examination or therapy • Functions include recording of duties. • Connecting to Google Calendar • Suitable for use by a caregiver	• Complicated UI design	•
Weekly planning Planner for school teachers indicating an improvement in a student's study progress	Physical 	• Graphic elements show progress improvement • Motivates the end-user to observe their improvement in daily life	• Development of a person with an LD will progress differently from the average student • This graph may create conflict between the caregiver and LDs individual	• Graphic design can be improved to make it more user friendly
SickKid Jewellery beads designed as a reward for being able to overcome the difficult process of hospitalisation.	Physical 	• Beads are an interesting type of jewellery. • Provides good interaction for typical and learning-disabled children • Beads create a growing number of positive feelings	• Includes no numbers or graphs • Jewellery receives different levels of attention among girls and boys • May not be suitable for adults with an LD	• The potential design outcome should take into consideration physical objects that are suitable for both genders.

Table 1 represents four key examples of products and services available for supporting caregivers. Carely and SickKid aim to monitor patient healthcare, thereby enabling caretakers to encourage patients as a means to motivate them during long periods of treatment. The remaining two apps are focused on education (Weekly planning) and helping parents to manage household chores with their children (iReward). Theses external research indicate examples of how rewards and tokens can be used effectively. However, all four designs noted here are aimed at people without LDs. In the current project, the researcher will apply positive reinforcement strategies for the caregivers of patients with an LD.

SUMMARY OF THE CONTEXTUAL REVIEW

The contextual review included four main parts. Firstly, a discussion of LD presents common syndromes, some of which overlap with ASD. The research includes caregivers providing services to individuals with LD and ASD. These individuals were categorised into low and high-functioning groups. The research identified common challenges in both groups.

Thai culture and Buddhism have impacts on caregivers' responsibility to care for their loved ones for the rest of their lives. Some Buddhist caregivers believe in the law of karma.

Coping strategies focus on applying positive reinforcement (rewards and tokens) in the caregiving process. Finally, market research indicated the use of a token economy in different areas such as education, medication, and normal household activities. However, none of these designs offers specific functions for responding to the challenges faced by Thai caregivers of people with an LD. As such, a potential gap exists in this regard.

METHODOLODY

This research project aims to develop a tool or process for assisting a caregiver caring for an adult family member with an LD in their day-to-day tasks. The research is based on design thinking methodologies using a qualitative approach (see Figure 2). Design thinking includes several tools and processes that allow the researcher to explore different creative design outcomes as options for responding to a problem (Crouch & Pearce, 2012).

As shown in Figure 2, three main processes were applied in the research (Martin & Hanington, 2012), i.e. problem framing, reflecting and problem-solving. The first step of problem framing involves initial research and analysis related to the issue at hand. Qualitative interviews were conducted with caregivers to gather data, which was then analysed using thematic analysis. A persona and customer journey map assisted in gaining insight from the data. The second step involves reflecting on the data by defining the research question (Lewrick, Link, & Leifer, 2018) and creating a problem statement. The third step is the problem-solving stage involving ideation, prototyping, and testing. The final step involves problem solving by designing the final outcome (Martin & Hanington, 2012).
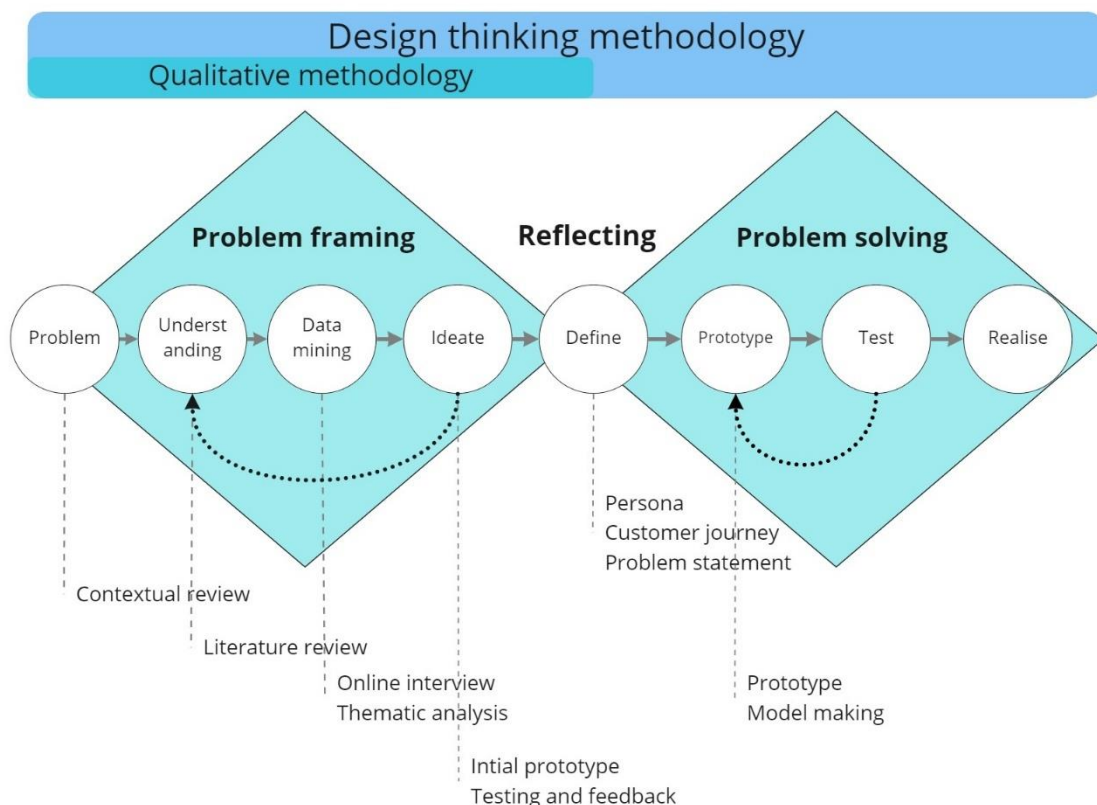
Figure 2: Methods diagram

METHODS

Figure 2 illustrates the eight steps in the design research. The process starts by defining the problems and ends with realising a potential solution. Seven methods were used in the research as follows.

- Contextual review
- Online interview
- Thematic analysis
- Persona
-
- Customer journey
- Problem statement
- Prototyping and testing

PROBLEM AND DATA MINING

The literature review was undertaken to formulate a deeper understanding of the research question and background problems related to Thai society, culture, and Buddhism. Additionally, LD syndrome and the autism spectrum were explored. In the following section, data collecting through online interviews, data analysis employing the persona method and thematic analysis, and the prototype method are demonstrated in more detail.

UNDERSTANDING

ONLINE INTERVIEW

Online interviews were conducted with Thai caregivers to construct a framework for understanding the behaviours of people with LDs and the challenges caregivers face, based on their individual perspectives (Laurel, 2003). The researcher conducted interviews with six Thai caregivers, which were divided into two categories, i.e. three sibling relationships and three mother–son relationships. The gender of primary caregivers was female because, in Thailand, it is typically women who are responsible for taking care of children with LDs at home, with men employed outside the home (Gray, 2003). Five participants among six were female and one was male (see Table 2). The interviews were conducted online via Skype voice call to gather qualitative data.

No	Name of caregiver/ gender	Occupation	Relationship with the LD individual	Gender/age of people with LDs/group type	Number of children in the family (including the participant if they are a sibling)
1	Chao/male	Business owner	Younger brother	Male, 36; high-functioning autism	2
2	Bee/female	Artist	Older sister	Male, 25; high-functioning autism	2
3	Pra/female	Co-founder of an LD organisation	Mother	Male, 25; low-functioning autism	1
4	Samand/female	Restaurant owner	Mother	Male, 22; low-functioning autism	3
5	Rawee/female	Interior designer	Mother	Male, 23; high-functioning autism	2
6	Lanna/female	Marketing consultant	Younger sister	Male, 32; low-functioning autism	2

Table 2. Participant demographics.

The researcher contacted potential participants via email to inform them about the questionnaire and the structure of the online interview. The researcher search contacts of participants from the Autism Society in Thailand Facebook group, and others were introduced by the participants that had already been accepted to the study. I had not met any of the participants previously. In addition, Thai caregivers caring for an adult (aged 18 and older) with an LD in their family were selected. The researcher aimed to discover patterns related to insights, problems, and challenges experienced by family caregivers of a family member with an LD.

The interviewees were asked questions about the problems and challenges they faced are

caregivers, as well as the solutions they applied when providing care for adults with LDs at home (see Appendix 2).

The researcher initiated the interview by asking the participant for their definition of the term 'learning disability'. This aimed to delineate their understanding of the condition and served as a preparatory conversation before addressing their personal experiences. The remainder of the questions aimed to gather insight into what it meant to care for an adult with an LD in terms of individual challenges and daily routines. The final section of the interview aimed to investigate the coping strategies that Thai caregivers commonly applied and reflected on successful strategies, as well as why some others did not work.

The interviews were subsequently transcribed and used for data analysis. Thematic analysis was chosen to examine the data gained from the online interviews. The researcher used the problem-framing phase to define the problem position and context surrounding the research problem.

THEMATIC ANALYSIS

Thematic analysis was selected to analyse the data as it was suitable for application to poorly acknowledged topics gained from interviews and focus group (Braun & Clarke, 2006). The purpose of the data analysis was to understand participants' purpose for being caretakers and to draw conclusions (Martin & Hanington, 2012) about the main challenges and barriers they had to deal with when caring for a person with an LD in the context of Thai culture.

There were six steps in the analysis process (Braun & Clarke, 2006). Transcripts generated from the interview recordings were part of the first phase is familiarising with the data. Following on, primary ideas were recorded after reading and re-reading the transcripts. Several key quotes were highlighted and arranged in a table, e.g. those related to problems regarding the educational system, family, and culture.

The second step was coding the data. In this phase, the researcher systematically coded interesting topics across the entire data set and collected data relevant to each code.

The third step involved searching for themes by collecting all codes into potential key themes. A mind-mapping tool was used to collect the codes into the potential themes and to map all data relevant using a table and colours. The fourth step was reviewing themes. During the theme searching process, 10–20 topics were highlighted. Reviewing was a critical step in narrowing down

themes into five categories. This was a back-and-forth process. The fifth step involved defining and naming themes. This phase aimed to refine the specific name of each theme. Names were selected to represent the content of the data analysis and supporting quotes provided by participants. Through this process, the overall story and the analysis of narratives were illustrated. The researcher generated clear definitions and names for each theme and during finalisation, themes were merged into two main categories.

The final phase involved writing up the analysis report, relating the analysis to the research question and an additional literature review. The written thematic analysis report included relevant data and support materials.

DEFINE

DESIGN THINKING TOOL

A stakeholder map was selected to identify key components in user values, actions, and beliefs (Martin & Hanington, 2012) (see Figure 3). The research defined the challenges experienced by the caregivers of patients with LDs, as it was important to understand the ecosystem surrounding the user.
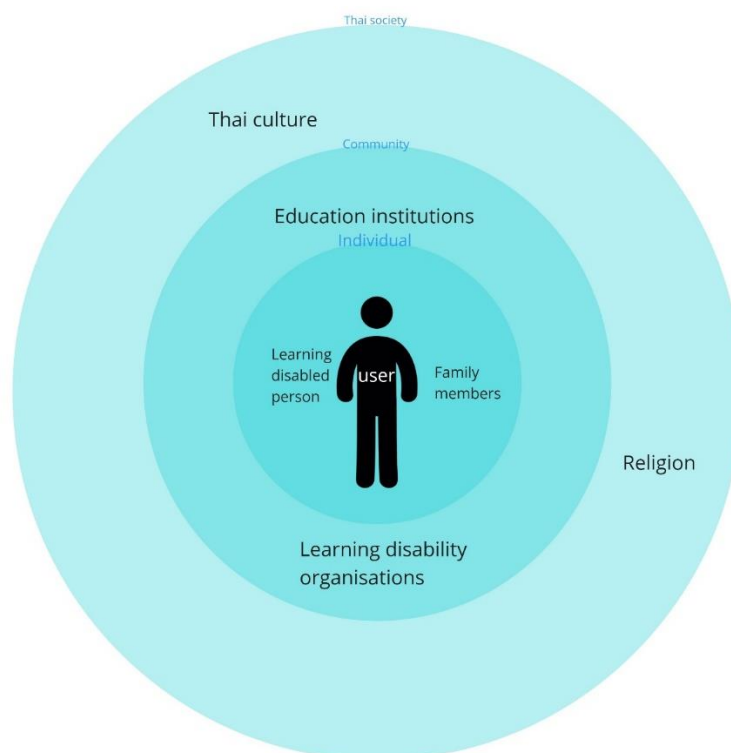
Figure 3: Stakeholder map.

PERSONA

'Personas are fictional characters, which you create based upon your research in order to represent the different user types that might use your service, product, site, or brand in a similar way. Creating personas will help you to understand your users' needs, experiences, behaviours, and goals' (Soegaard, M. ,2018)

The persona was analysed based on participant insights. A persona is a tool for analysing end-user personality (Martin & Hanington, 2012). This method was deemed suitable for the current study, which aimed to create a service design for a niche market by focusing on the Thai caregivers of adults with LDs. A persona is a crucial tool for understanding the target user in terms of personal characteristics and insights, and the customer's experiences of gain and pain.

CUSTOMER JOURNEY

The customer journey tool was used to analyse the participant's caregiving experience. This journey (see Figure 7) it separated their experiences into three phases, i.e. before the design, and during and after service (Sorman, n.d.). The researcher used the customer journey tools to understand the Participant in this research's overall experience. The customer journey helped the researcher to realise broader perspectives and to formulate the design outcome prototype based on real scenarios involving the target user (Martin & Hanington, 2012).

PROBLEM STATEMENT

A problem statement is an approach for defining a key problem into one or more sentences. Such a statement helps to narrow down the problems at hand, thereby making them easier to manage. Conversely, the problem statement should not be too narrow and should expose additional design opportunities (Muratovski, 2016). This approach supported the researcher in minimising the research problems. A problem statement will help to formulate design criteria for creating the model in the prototype process.

PROTOTYPE AND TESTING

PROTOTYPE

A prototype was used to experiment with the design solution. The initial prototype was used and tested via an ideation phase to gain feedback from real users. This aimed to improve user interaction with the prototype. Testing and ideation was a back-and-forth process (Martin & Hanington, 2012; Reay et al., 2017). Following on, the problem statement was defined based on user insights.

The outcome of this research may result in formulating a new service design. This service system will be designed to assist a family caregiver in their daily tasks. During the design process, design theory and data analysis of the literature review in the first and second phases were applied to design the final outcome. Sketching and creating a prototype were effected to represent the conceptual design (Reay et al., 2017).

The prototyping method required the practical skills involved in user experiences alongside the user interface (UI) design to create an application (Allanwood, 2014). This prototype stage included a human-centred design approach and application of the psychological theory of motivation (Weinschenk). The previously discussed reward system features were applied in UI design. Sotirakou, Papavasiliou, Mourlas and Isacker (2015) showed that the reward system had an effective and positive impact on providing medical care to people with an LD and the elderly. The researcher adapted and applied the reward system concept from a gamification-based approach (Cugelman, 2013).

TESTING

An output was developed from the analysis phase in the form of a mock-up prototype. Testing was conducted to gather feedback about the initial prototype as a means to develop the final outcome. Four participants were re-interviewed in testing stage. Three of the four participants gave comment on the initial prototype in ideation state. Two participants voiced their opinions following the defining process, one of whom was re-interviewed twice during both processes.

ETHICS

The researcher applied for ethics approval for the present research through the ethics committee of Auckland university of technology AUTEC and was approved to proceed on 4 December 2019. Ethical issues were considered related to the interview and focus group co-design process. The information-collecting process involved interviewing the caregivers of individuals with LDs via online video conferences. This data collection process was selected for gaining valuable information from real user perspectives. This information assisted in validating the design criteria and allowed the researcher to understand the user journey.

Prior to conducting the interviews and gathering data, the researcher and her supervisors agreed on the methods (noted in the methodology section) that would be used. The discussion of research methods assisted the research process as a whole, within a particular sequence, academic framework and within a specified time frame. The researcher converted the co-design workshop into an online testing prototype in August (2020) due to the Covid19 situation, which affected the research process. This method was adapted to fit within the allocated time frame.

Since this process involved conducting interviews, participants' personal data and privacy had to be protected. Names were concealed using pseudonyms, thereby ensuring participant anonymity. Both the researcher and the interviewees signed a consent form (see Appendix 1). The participants were also sent an information sheet via email prior to conducting the interviews and were allowed to pose any questions they had about the process (see Appendix 2). The interviewer primarily used the Thai language and the researcher translated the interview into English. The information received from interviews was used with the consent of all participants. The translation was also checked to ensure its correctness prior to using the data.

RESULTS

THEMATIC ANALYSIS

Challenges at an individual level	Challenges at a community level
1. Past experience; difficulty understanding LD syndrome and accepting their role as caregiver	2. The impact of Buddhism on family caregivers
5. Caregivers feel unsupported by other family members	3. The societal pressure experienced by families with learning-disabled members
6. Coping strategies and the opinions of others; supportive tools for home caregiving	4. Lack of community support
7. Emotional struggles experienced by the caregiver	

The researcher focused on investigating the challenges faced by Thai caregivers. Thailand is a developing country in Southeast Asia where LDs have a unique cultural context that differs from other countries. I interviewed six caregivers of Thai family members with LDs to understand their caregiving experiences and the challenges they face (see Table 2). The challenges affecting caregivers are divided into two main areas, i.e. community and individual sections (see Figure 4).

Figure 4: The final themes derived from thematic analysis.

CAREGIVERS STRUGGLED TO UNDERSTAND LEARNING DISABILITY SYNDROME AND ACCEPTING THEIR ROLE AS CAREGIVER

When I asked participants, what being the caregiver of a person with an LD was like, they discussed the challenges of having to initially learn about this condition and accepted their role as caregiver Pra, for example, shared her experience of the moment when she realised all of her past parental knowledge was non-applicable to caring for her learning-disabled son and that she had to learn everything from the beginning.

'The word of learning disability doesn't change my son for me, this word doesn't mean anything... But it means the knowledge your parents have passed down to you cannot be applied with learning disabled kids; you have to start learning anew from the beginning to understand and take care of them.' (***Pra***)

When parent caregivers realise that their existing parental knowledge cannot be applied to caring for their learning-disabled child, they begin to develop their understanding of LD syndrome and how to take care of a child with special needs. The parent caregivers I interviewed experienced different instances in which they came to understand that their loved one had an LD syndrome, with some receiving an early diagnosis while others were diagnosed at a very late stage. They all struggled to understand the consequences of this, both for themselves and their family. Bee talked about the meaning of LD, the stress of having to communicate this to other people in Thai society and having them understand this context.

'People with learning disability are actually like normal people, it is, in reality, something natural... If I had a hearing impairment, I would need other people to speak up or would need some special tools to help better my hearing. This is merely natural, but we just make a self-assumption that this lack of interaction is not normal...just treat LD like treating other normal people in society. Our self-assumption seems to prescribe us to use separate special methods to treat children with special needs.' (***Bee***)

The participant stated that it would be better if people in Thai society had a better understanding of LDs and treated people with such a disability the same as everyone else. Caregiver are concern what other people thinking about them. Thai culture, particularly Buddhism and social norms, had a significant impact on caregiving roles.

THE INFLUENCE OF BUDDHISM ON FAMILY CAREGIVERS

Buddhism has a significant impact on the role of caregivers in Thailand. As the national religion of Thailand, Buddhism is practised by 80%–90% of the Thai population (Barbara M Fulk, Swedlik, & Kosuwan, 2002). Half of the study participants agreed that the teachings of Buddha helped them to be mindful. According to these teachings, Buddhists bring their mind into the present moment and assume their responsibilities to the best of their ability. Subgranon and Lund (2000) explained that Thai caregivers have strong religious beliefs that affect their caregiving role and their approach to tasks.

Branon and Lund (2000) explained the belief among Buddhist caregivers that the reason patients become ill (and they become caregivers) is based on the past deeds of both parties in previous lives. Accordingly, they accept the law of karma and will continue caregiving for the rest of their lives. Being a caregiver requires dedication and consistency to provide adequate care. Providing care to those with LDs is a life-long task. Chao described his role as a caregiver as follows:

'We are not only brothers, but I have a role as his guardian and teacher as well. My family and I have to do everything for him to make sure he feels comfortable. I just thought that destiny made we were born; we are live together. I cannot let him live a troubled life, I just cannot. In the future, when he gets older, I will still take care of him. I must take care of him the best for the rest of my life.' *(Chao)*

Buddhist beliefs have a direct impact on the role of caregivers. They apply the principles of Buddhism to avoid stress and depression when faced with anxiety about maintaining a caregiving role. Bee, for example, talked about the benefits of Buddhism in this regard. She applied its principles in a bid to stop overthinking, to allow her to focus on the present moment, and to encourage her to be the best caregiver possible.

'I used to have a question like what if I'm not here? Who would take care of my younger brother with learning disabilities? My major goal at the moment is to live in the present the best I can just like what the Buddha taught us. I need to do the best I can today to enable him to stand on his own two feet as much as possible.' (*Bee*)

Caregivers take care of people with LDs for a long time, which may cause sadness and stress. Zarit (2006) found that 40%–70% of caregivers suffered from symptoms of depression. The research also showed that '17% of caregivers feel their health in general has gotten worse as a result of their caregiving responsibilities' (Purvis, 2008). Religion may be one of the tools that Thai caregivers employ to remain grounded, to help them to cope with difficulties, and to provide themselves with an intellectual explanation as to why they take on the responsibility of caring for a LD individual.

SOCIETAL PRESSURE ON FAMILIES WITH LEARNING-DISABLED MEMBERS

A sense of belonging and being accepted is vital within Thai culture. Thailand is a collectivist culture. Hofstede (1984) described collectivism as the notion that people prioritise the good of society over the welfare of the individual. In such cultures, the needs of the group are emphasised over those of the individual, which affects the meaning of 'belonging' differently compared with an individualist culture, where the focus is on the individual. This mindset affects family caregivers because they are viewed as different from others, and their role as caregiver carries a social stigma.

The participants and their family can feel isolated and may find it difficult to fit into Thai society. As such, caregivers not only have to ensure that their family member with an LD is well-cared for but also worry about living in harmony with the majority of Thai society. Some caregivers remain concerned that Thai society may not understand and accept them. Bee shared her experience when her brother reacted emotionally in a coffee shop:

'I need to let society know why I have to scold him when he expresses his emotions in public. I'm not a devilish monster I just need to explain… Society needs to learn not to get emotional when interacting with children with special needs.' (**Bee**)

Bee believed that caregivers and the surrounding community could support people with an LD by understanding them better. Fox, Vaughn, Wyatte, and Dunlap (2002) stated that the majority of Thais may lack an understanding of the symptoms linked to LDs because they are often invisible. It may thus be difficult for Thai society to immediately recognise these symptoms, considering that people with an LD's outward appearance is the same as everyone else. The symptoms of LDs are often expressed in different behaviours, such as an overly emotional reaction in public. All the study participants stated that these situations sometimes created tension and humiliation for caregivers. The issue remains a continuing challenge and caregivers want Thai society to understand and become more aware of the problem of LDs.

LACK OF A COMMUNITY SUPPORT SYSTEM

The participants felt they did not receive the proper support from healthcare and education providers. Samand shared her experience of having to choose between spending on her son's education, or saving it for his future:

> 'My main goal has gradually changed … I once expected my kid to finish the highest level of education he could … we went to many schools, I joined learning disability group in the past, but in the end, they cannot help us. I spend a lot of time and money I think I'd better save up that large sum of money for my son to spend when he gets older.' (***Samand***)

The bulk of caregivers included in this research expected their family members with an LD to be able to complete the highest possible level of education, based on their potential. However, specific education courses for people with LDs in Thailand are not yet broadly accessible. Specialised education is expensive, which narrows down the options for caregivers, some of whom opt to save money for home-based care instead. A qualified special education is not easily accessible to all families of people with LDs. Samand discussed the high cost involved and the competition involved in being accepted into a special school:

> 'I've considered one of Thailand's well-known universities' bachelor program for students with special needs. However, you need to either have a connection and privilege or be able to pay enormous additional charges to be eligible for this program. Unfortunately, we are neither.' (***Samand***)

Rather than sending children to specialised schools, some Thai parents prefer to send their children with LDs to study alongside regular students. Rawee, for example, chose to attend classes with her son so he could keep up with lessons:

> 'I join classes with my son, sitting right next to him, and find that some classes are way beyond his learning level. Sometimes, we were both forced to be excluded from the class because he could not catch up with some lessons.' (***Rawee***)

It is difficult for caregivers to admit that their loved ones will at some stage no longer be able to remain in the academic education system. Rawee admitted having to change her expectations regarding her son over the course of his schooling. Accordingly, most caregivers included in the current study' decided to educate their children at home.

Many challenges exist within the Thai education system. This includes a lack of broad access to good Thai education and special schools, resulting in the majority of Thai caregivers included in this study opting to take care of their learning-disabled family member at home with family support. Lack of supportive systems is an important issue that can be addressed through the development of the

Thai education service system for people with LDs. This falls outside the scope of the present study. As such, the researcher opted to focus on gathering insights about caregiving at home and the challenges of collaboration between family members as a potential area for designing solutions.

THE CHALLENGES OF FAMILY AND KINSHIP SUPPORT

Once parents decided to look after their learning-disabled children at home, other family members become important touchpoints. Primary caregivers will expect help from other family members, who would take on different roles. Fox et al. (2002) discussed building a caregiver's team to support caregiving systematically. This support can, for example, be a simple form of emotional support. Caregivers and family members working together as a team can have a positive effect on long-term care. Bee expressed the challenges of getting other family members to share the workload:

> 'The problem is… I can't convince other family members to have my brother do activities like I do… Everyone has an excuse… I feel that if we need to support his development, everyone in the family needs to actively cooperate… It is a kind of challenge to persuade other family members to get involved, not just me as a major caregiver.' (***Bee***)

The expectations of a person with an LD being regularly supported by everyone in the family has become the ultimate challenge that caregivers have to deal with.

THE GOALS OF CAREGIVERS

The researcher asked the participants about their motivations and goals. Pra confirmed her determination to take care of her son until the last day of his life. Her son passed away three years ago.

'My aim is to let his potential of being a child with special needs fully shine the way it is.' (***Pra***)

The goal when caring for a person with an LD is for them to live a full life. While this may sound simple, it is 'easier said than done'. Pra explained this to be the most challenging aspect commonly shared by herself and other parents of a group therapy.

> 'The most challenging task is to figure out how to enable children with special needs to lead a normal daily life with their families…similar normal daily activities at a normal pace every day… The challenge is for the kids to be able to deal with any changing condition in their daily life.' (***Pra***)

Learning disabled people and caregivers spend most of their time at home. Finding appropriate activities and equipment for people with LDs can be time-consuming for caregivers. These activities

must help develop the skills of a person with an LD. Chao talked about the challenges that arose due to his brother spending the majority of life at home.

> 'The challenge we encountered was on finding activities that suit his ability level and interest and can keep him concentrated since he is quite hyperactive. The right activity can keep him concentrated much longer than normal people.' (*Chao*)

Caregivers sought out activities that suited both their skills and the interests and those with an LD. Activities that caregivers currently use primarily include art therapy, such as colouring books and painting canvasses. They also engaged in handicraft activities with different materials such as wood and ceramics. The researcher was interested in therapy activities that could be conducted at home.

COPING STRATEGIES AND OPINIONS OF OTHER SUPPORTED TOOLS USED WITHIN HOME CAREGIVING

The researcher discussed the strategies that caregivers typically used for managing people with LDs at home. Three main strategies were highlighted: positive reinforcement (i.e. conditional rewards), negative reinforcement (i.e. scolding and punishment), and quality time.

POSITIVE REINFORCEMENT

Positive reinforcement was a popular strategy used by all participants and was used to provide pleasing results for both caregivers and learning-disability individuals. Positive behavioural support was noted as having both a positive impact on the quality of life of the individual being cared for and their families and decreased inappropriate behaviour (McKenzie et al., 2018). The participant selected a reward using simple items such as snacks, drinks, toys, or small objects that their loved ones were interested in, or provided their favourite outdoor activities. Chao described how he motivated his brother to participate in joint activities alongside him, such as jogging and painting:

'The trick is positive encouragement, such as we will go out after he finishes a particular activity. His doing good thing will be rewarded like eating out or getting his favourite food or buying a new colouring book … But if we are too busy, we might negotiate.' (**Chao**)

Caregivers aim to improve their loved ones' behaviour and may sometimes reward good behaviour in the hope that it will change inappropriate behaviour. Bee used this method to teach her younger brother:

'Rewards are used as an incentive, i.e. dessert and travelling abroad… I will carefully observe what his particular interest is at the moment and use that as a keyword. When he is disobedient, I'll tell him that I won't take him to where he wants to go.' (**Bee**)

The above serve as examples of positive reinforcement shared by the participants. The bulk of reinforcement occurred in the form of gifts. The analysis of this research shows that a token economy (reward points) approach was not mentioned by participants to their loved ones. The initial insight that 'positive reinforcement will be an effective strategy in daily activities at home' appeared to be partly true. Participants used gifts as a type of positive reinforcement on special occasions. Next, negative reinforcement and attitudes towards this approach are discussed.

NEGATIVE REINFORCEMENT

The researcher found that caregivers did not only use reward strategies but also negative reinforcement approaches, such as punishment when an LD person engaged in inappropriate behaviour. Caregivers considered a balance between punishments and prizes as an essential part of managing behaviour. The researcher noticed that parent caregivers felt uncomfortable about describing the punishments they applied with their LD children at home. Parent caregivers explained that it was logical to use some penalties, such as scolding and hitting when LD people acted aggressively. Samand shared her strategy of using punishment and reward with her LD son in reference to a day she had to manage his heightened emotional state. She also mentioned balancing the use of punishment and reward with her son, who had low-functioning autism with aggressive behaviour.

'When he grows up, I think just punishing him by hitting would not work but giving him rewards like snacks and drinks would be unhealthy. So, I'm not sure. I have to keep the balance. I try to make him stay still but sometimes I fail to do so. When he starts to rant, I need to yell at him sometimes.' (**Samand**)

The participant who used punishments noted that 'either positive or negative reinforcement alone may not always be suitable, and a combined strategy appears to work best'. However, the idea of violent punishments was not acceptable to all participants; specifically, all sibling caregivers disagreed about using such an approach. In addition, they commented that rational discussion and explanation is critical.

'I disagree with the idea of using violence. I do not think it works. I think it's better to talk and clearly explain without physical punishment.' (**Chao**)

The researcher noted that some of the participants were caregivers of high-functioning LD people who were able to control their own behaviour better than those with low-functioning autism. This may have resulted in different opinions about the use of physical punishment as a form of negative reinforcement. In the interviews conducted for this study, three among four caregivers of high-functioning LD people disagreed with the notion of punishment; one participant refrained from commenting on the idea of punishment. Two caregivers of people with low-functioning autism stated that they sometimes used physical punishment when LD people behaved violently.

ATTITUDES TOWARDS PHYSICAL TOOLS AND DIGITAL DEVICES

Some caregivers expressed negative views about the use of digital devices. They were concerned about excessive use and how it may affect their loved one's cognitive functioning. They believed that by applying digital devices, the individual with an LD would be deprived of physical experiences. Digital devices were observed as relating to a sense of carelessness by caregivers:

> 'I think parents who just gave smartphones to their kids are lazy and careless. I'm sorry to have to say that but there are so many other ways to replace that activity…but digital devices might be the easiest way for them.' (**Bee**)

In contrast, in the families of LD people who behaved violently, caregivers discussed positive integrated strategies, such as using digital devices or digital game consoles. These tools were attractive to LD children and could help them to relax.

> 'My son has his behaviour treated through a singing therapy. He sings old Thai songs. He will open his iPad and sing… when no customers in our shop I am not serious about his voice. He sings just to make him enjoy and be in a good temper and to me, that's the golden moment.' (***Samand***)

Attitudes towards the use of digital devices in assisting caregivers in their daily tasks remain unclear. The effectiveness of these devices depends on the purpose for using them, the degree of use, and whether caregivers view them as beneficial or harmful.

EMOTIONAL STRUGGLE

FEELING OVERWHELMED

All participants believed that sharing quality time with their loved ones was more important than any physical or digital device. Samand stated that she gave her son many toys but what he wanted the most was for her to play with him:

'More importantly, he needs me to be there with him. He loves to have someone to play with him. Unfortunately, I do not have much time to spend with him... Actually, he needs a person to stay with him and talk with him the entire day more than a toy.' (**Samand**)

All participants stated the most important part of caring for LD people as sharing quality time with them. This quality time referred to moments in which they shared positive (i.e. fun, happy) feelings. Participants also needed quality private time on their long-term caregiving journey. Pra discussed her 'bad days' when she had to deal with the emotional outbursts of her LD son:

'My worst-case scenario would be the disastrous day from dawn until dusk when our kids with special needs couldn't cope with some particular domestic situations. The challenge is for the kids to be able to deal with any changing condition in their normal daily activities at a normal pace every day and for me too.' (**Pra**)

Caregivers required patience and had to hide their personal feelings to cope with daily emotional and chaotic situations.

CHALLENGES FACED BY CAREGIVERS TO MAINTAIN THEIR OWN LIFE EXPECTATIONS

The researcher noticed while conducting interviews that it was difficult for caregivers to articulate their own needs when asked about making them a priority. Rawee shared a story about the moment in which she had to choose between her career and her son. She became a successful caregiver who was able to establish a small handicraft business with her son:

'Back then, I still did the job I loved and felt passionate about. Later on, when I realised that my kid had special needs, I initially struggled with parenting. I needed to quit my job and be a full-time mom.' (**Rawee**)

The researcher noticed that both parental and sibling participants appeared to struggle when talking about their life expectations. Female caregivers were aware of the obligation to manage their personal lives and their role as caregiver. Lanna stated (in a low tone of voice) the difficulty of admitting the weight of caring for an LD person at home.

'I want to study for a PhD. I have my life to live. I was trying to tell my mom that my brother could find a way to live a self-sufficient life... But in the end, the person who decides for him is her. She did not want my brother to have a difficult life.' (***Lanna***)

The participants confirmed the difficulty of encouraging their families to be open-minded, and to accept and help LD family members to receive help and access quality services. This was linked to the Thai collectivist culture, which requires the coexistence of family members, rather than living independently. The participants noted that it was difficult to articulate the term 'independent living' in their family. Expectations of care delivered by family members can be a sensitive topic in Thai culture. The research results refer to this point to some degree but it was not a main concern of the study. The design solution may suggest an alternative service design but without any attempt to convince customers to change their beliefs or behaviours.

The concept of independent living is new to Thai culture. However, issues pertaining to LD people living independently were not included in the current research. The main focus was caregivers' freedom to focus on their own life expectations and to recognise the value of pursuing their career and educational paths. This issue not only affects the quality of life of a single individual but also other family members.

EMOTIONAL COPING STRATEGIES

McCurry, Logsdon, Teri and Vitiello (2007) found that two-thirds of caregivers who provided long-term patient care experienced sleep disturbances. These caregivers were in a situation where someone they loved was weak, and among the first things to be sacrificed were adequate sleep, nutritional food, and exercise. It is important to demonstrate how important self-care is for caregivers. When caregivers experience long-term neglect, it will affect their ability to care for someone else. The researcher investigated existing techniques that caregivers could use to reward or calm themselves. Rawee shared the strategy she used to manage her feelings by distracting herself with painting or art. She also talked about spending time with her pet.

'When I face the situation, which is out of control, I sometimes go to my dog. Pets are really good when you need some hugs to hold onto. Actually, I just need something like a cat to distract my mood. It could help me to stop thinking, calm me down, and bring me back to consciousness. It helps me to get ready to continue my duty.' (***Rawee***)

The researcher observed that caregivers needed time to relax and to fulfil their personal needs. It was important for them to be able to rejuvenate and have quality breaks before returning to a caregiving role. These periods also helped to remind them of their values and reinforced their sense of self-identity. Having time to relax provided rest and returning to a caregiving role with hope.

SUMMARY

The thematic analysis chapter can divide the challenges that caregivers face into two parts. The first part covers the challenges that arise from the community and Thai society. The second part concerns challenges at the individual level. The focus of this research was the personal challenges faced by caregivers in maintaining their life expectations while caring for LD individuals. Figure 5 presents a thematic analysis diagram of the factors involved in doing so.
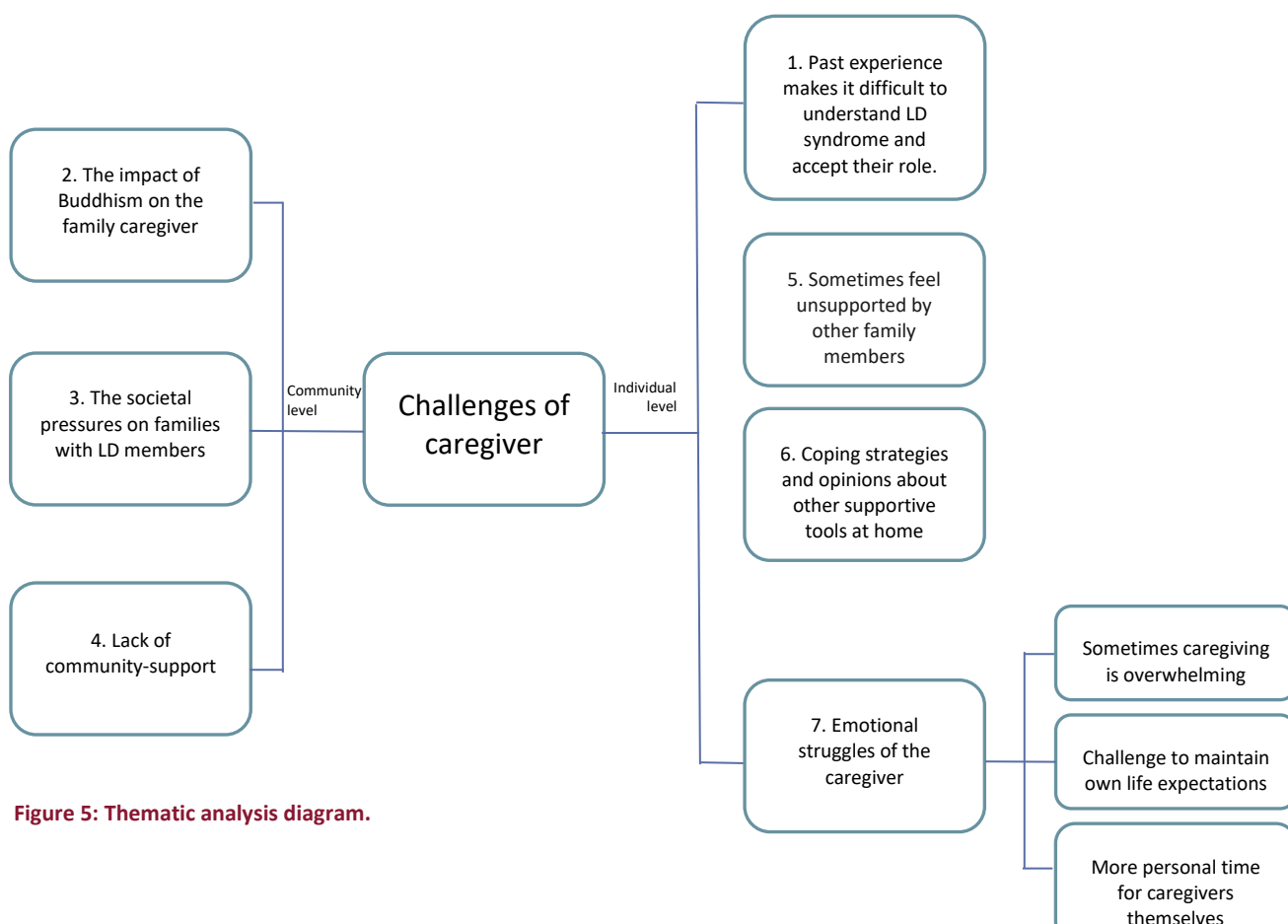
Figure 5: Thematic analysis diagram.

The challenges of maintaining their career were highlighted as a critical issue by all participants, particularly female participants (more details related to gender issues are given in Table 3, based on three personality types).

The concept and development section will discuss the problem statement of this research in more detail and solutions will be presented in the final design outcome.

REFLECTION

In this chapter, the researcher provided an overview of Thai society, which had an impact on the participants (e.g. culture and religion). These issues were primarily the reasons for Thai caregivers opting for home care, based on the lack of comprehensively accessible social support services. Thai society is a collective culture and all the participants lived with their family. In this context, caregivers living independently reflected a novel mindset. For caregivers, pursuing their career and educational paths presented challenged in the context of Thai culture. The research concluded that there was a need for advocacy services to help individual caregivers take control of their personal time.

In the next chapter, this problem is defined in more detail using the design thinking method to gain a deeper understanding of the challenges involved and to formulate problem statements. The final part of this report demonstrates the research outcome in the form of a design proposal.

CONCEPT AND DEVELOPMENT

This section is divided into two parts: the design concept and the development of the design outcome. The concept was generated based on user insights and by applying user-centred methods. In the first section of the chapter, the design thinking tools, such as persona, customer journey, and problem statement were selected to demonstrate data and generate design ideas. Development of the design outcome is discussed in the final part of the chapter.

PERSONA

The persona aimed to emphasise the role of caregivers and the challenges they face. The demographics and qualitative data of the participants were collected to design the persona (McKenzie et al., 2018). In this research, participants represented three key groups, which were based on their relationship and the level of responsibilities on caregiver's role. These three groups represented different segments of Thai caregivers. An essential classification factor was the bond between an LD person and the caregiver's role in terms of family and career.

Members of the first group were dedicated caregivers who provided full-time care to LD people. The second group were employed caregivers who worked and took care of LD people at home. The third group were auxiliary caregivers, most of whom served as secondary caregivers.
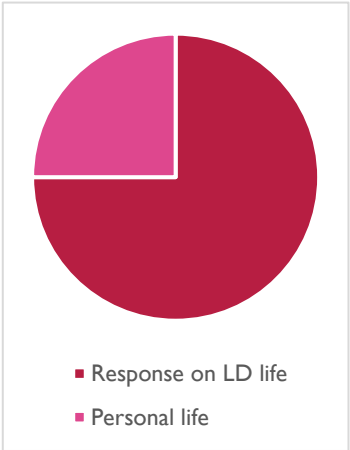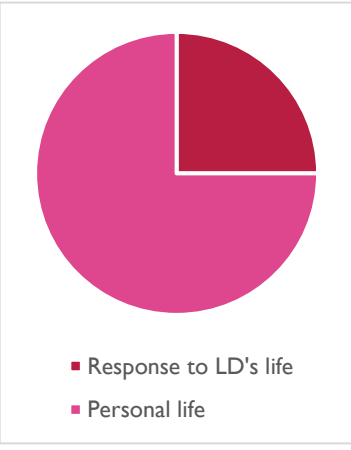
Type	Dedicated caregiver	Working caregiver	Auxiliary caregiver
Description	A primary caregiver devoted to caring for their son	A primary caregiver who tried to balance their time between taking care of their loved one and living their own life	A secondary caregiver who made their own life their priority
Proportion of involvement in an LD person's life	Response on LD life / Personal life	Response on LD life / Personal life	Response to LD's life / Personal life
Job title	Full-time housewife	Freelance artist	Full-time financial analyst
Goal	Support their LD son for the rest of their life	Take care of their loved one and simultaneously pursue their own career goals	Be supportive when others experience difficulties
Relationship with an LD person	Mother	Sister	Brother

Table 3: Three persona types.

The target group was the group of working caregivers. There was no specific relationship in this group (they could be siblings, parents or both). This group was selected for the following reasons. First, the data analysis revealed a need for support, particularly in terms of enabling caregivers to focus on their own lives (e.g. career and further education). Second, this group had to maintain a balance between their career and their caregiving tasks. The persona developed for Ratda represents the target user of this research.

Ratda is a female primary caregiver for her younger brother with an LD (see Figure 6). Her pain point is reflected in the challenges she faces to pursue her career goals while at the same time taking care of her disabled brother. The background for the characterisation of this female caregiver was derived from data analysis.

REFLECTION

The key issue in this case was a gender issue linked to caregiving. The findings revealed that gender played a primary part in the role of female caregivers (see Table 2). Gray (2003) noted that in the United States of America, there was a greater number of female than male parents acting as primary caregivers.

The researcher recognised that a service must be made available to assist working caregivers who looking after special needs individuals. Caregivers' lack of time to address their own needs and achieve their own goals represent the challenges that the present research aims to respond to through design.

Working caregivers

Name: Ratda Wattachai

Gender/age: Female/aged 32 years

Nationality: Thai

Place of residency: Bangkok (capital city), Thailand

Occupation: Freelance designer
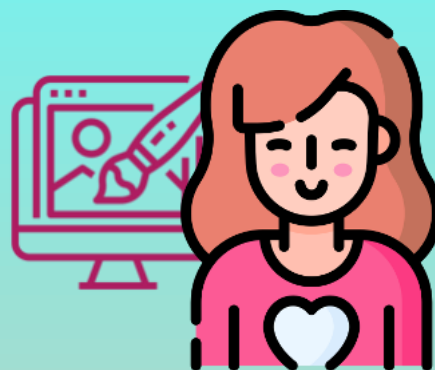
What are their goals (what are they trying to achieve)?

Ratda tries to maintain a balance between her personal goals (becoming a well-known designer) and her role as caregiver for an LD person (her brother) at home.

What are their frustrations (pain points)?

Ratda feels alone in having full responsibility for caring for her younger brother. She is the only person in the family who can work at home. As a result, she has become a full-time caregiver and a part-time employee in the job that she loves.

Who are they? What is their personality type?

Ratda is the middle sister of three siblings (she has an older brother and a younger learning-disabled brother). She is single. Her oldest brother was married four years ago and has a child. Ratda is a "yes" woman who finds it difficult to say "no" to others. She is kind and friendly. However, because of her too humble personality, she sometimes experiences a lack of confidence in herself. She is experiencing an identity crisis.

What are the issues they may experience with existing services? What do they desire from a new service?

Existing service: Ratda tried to hire a professional caregiver when she went abroad for a summer camp, but this was not successful (she changes caregivers every 3–6 months and one of them worked for only three days before quitting). The cost of hiring is also too high and she has additional expenses in the form of her father's hospitalization. Her parents decided to ask her to become a full-time caregiver after hiring a nurse who worked for one year before quitting. Initially, her family helped to take care of the LD family member but after five years, Ratda ended up being the only primary caregiver.

Desires: Ratda wants another family member to keep in contact with her and learn all the necessary information about her LD brother (e.g. his medical profile) and a moment of quality time between family members in daily routines (your meaning is unclear here), so that she can have time to herself and focus on her own life and career.

Figure 6: Ratda's persona.

CUSTOMER JOURNEY

The research explored an in-depth meaning of 'quality time' using customer journeys to analyse caregiver experiences (see Figure 7). The customer journey tool represents the daily life of Ratda (the persona) by illustrating activities and how she interacts with other family members. This customer journey reflects the user's emotional state of mind by highlighting their pain points in three activities that reflect the most unsatisfying emotional scores. The activity with the lowest emotional satisfaction scale in the customer journey was personal work time (see the red column in Figure 7).
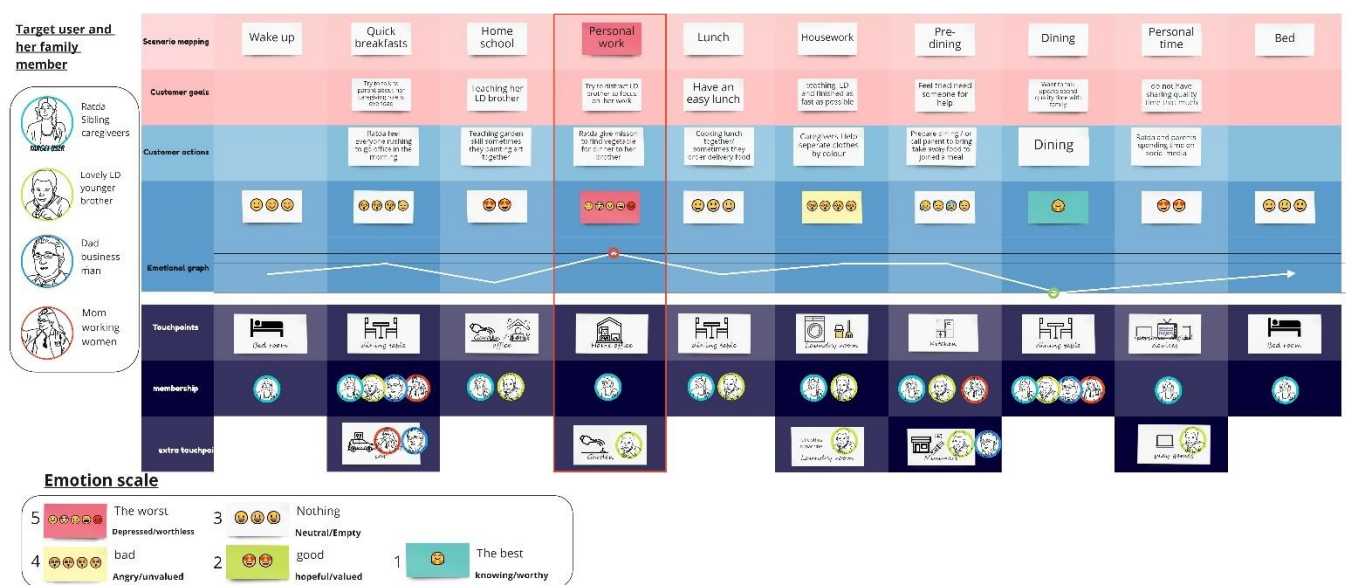
Figure 7: Customer journey.

A caregiver and an LD person may also experience frustration in the chore activity. The researcher concluded that a caregiver's personal time was the most suitable aspect to engage with in terms of service design outcomes.

PROBLEM IDENTIFICATION SECTION

The problem statement was developed from participant insights in the final section of the thematic analysis, which addressed caregiver challenges as they related to their personal quality time and sense of self-worth. The following is an example of a difficult moment experienced by a working mother who had to choose between her career and her son.

'Back then, I still did the job I loved and felt passionate about. Later on, when I realised that my kid had special needs, I initially struggled with parenting. I needed to quit my job and be a full-time mom.' (***Rawee***)

A different mother had to sell her business to be able to take care of her son full time Thai female working caregivers experienced problems in terms of managing their career and taking care of an LD person.

Problem statement
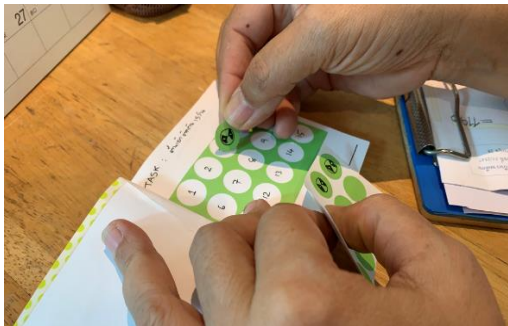
'Working female caregivers need a way to maintain their career because they feel pressure to accept caring responsibility above pursuing their career.'

Gray (2003) found that higher proportions of female caregivers than males had to face the challenges of being caregivers, particularly mothers of LD children. Existing research indicates the majority of participants acting as main caregivers were mainly female (Gray, 2003; Heller & Arnold, 2010). In the current research, all participants who were mothers had to choose between their full-time job and their special needs children. All of them quit their job to take on full-time care of their loved ones.

Lewis (2000) noted in research on dual-earner parents with disabled children that female caregivers in individualistic and collectivist cultures were impacted differently (Lewis, 2000, p.1055). In Thailand, where family care is crucial part of Thai collectivist culture. The current research's problem statement is critical in a Thai context. Lewis (2000) also recommended an increase in company policy and law to support parents with LD children.

TESTING PROTOTYPE AND CUSTOMER FEEDBACK PART1

Following an online interview in February, initial prototype testing of participant's caregiving challenges was conducted in early March in Thailand. The purpose of this was to receive feedback from real users. In this testing, a prototype was created based on the researcher's initial insights, derived from existing literature stating that positive motivation can have positive effects on care, and may help develop caregiver relationships with a special needs patient. The user test of prototype numbers 1–3 took place before analysis of the data gathered from the interviews, which provided initial insights about potential designs. This stage helped to increase an understanding of the problems experienced by participants and how they might respond to potential design prototypes. Three participants were asked to provide their opinions about each mock-up model. Subsequently, design numbers 4–5 were commented on in July 2020 (see Figure 9). Two applicants were asked about their opinion on these prototypes, one of whom was also included in the previous testing. The conclusions drawn from the feedback provided by participants is shown in Table 4.

No.	Name/date tested	Image	Feedback	Improvement
1	Behaviour-tracking sticker book 17/02/20		• Feels that a sticker book is for children, not suitable for adults with LDs • The person with an LD does not like to be tested or assessed by scores; they may be upset by such an approach • The number of rewards per page is limited (5–10 stars) and it is not easily adjustable • The design is unattractive	• If the purpose is to track performance, participants prefer whiteboards or calendars • They feel more comfortable using positive reinforcement for themselves but not with an LD person • Participants used money in an LD person's saving as a token; this sometimes-caused conflict between them. Token. is difficult to explain to a person with an LD

No.	Name/date tested	Image	Feedback	Improvement
2	Daily activity-reminder clock 29/02/20		• There is too much information on the front of the clock • The clock's physical form is not interesting; it reflects one-way communication.	• Requires simpler information graphics • It is not easy to change or adjust functions if there are changes in the daily routine
3	A reminder apps 29/02/20		• Applications are more interactive • Interactive functions between caregiver and other family members	• The caregiver needs a tool that can remind her to do something good for herself, e.g. exercise. • Helps to distract the caregiver from her busy job and to prioritise self-care • Needs gamification features to interact with other family members (such as the features in a fitness smartwatch)
		• The next step involves data analysis of online interviews		

Table 4: Testing prototypes and feedback cycle 1.

REFLECTION

The researcher found the reward systems for caregivers useful in terms of participants being able to track their activities. They were receptive to this system but did not agree about using a token system with LD people. Testing prototypes in an earlier stage was extremely helpful and revealed aspects that did not work. The existing literature indicated that negative punishments tended to be effective. Subsequently, the data analysis of online interviews also showed that positive and negative reinforcements were not always effective and that a balanced combination of both was needed. Furthermore, participants felt uncomfortable about using rewards with LD people. Rewards in the form of a number-and-point tracking system may create conflict between a caregiver and an LD person.

It was found, however, that the function of a token system in prototype 3 was beneficial for the user when applied as a form of positive reinforcement for the caregivers themselves. Caregivers have positive feedback bout the reward system. Accordingly, this aspect would be used in the outcome using graphic design elements. Compared with using numbers, the UI will have a more user-friendly design. The design elements will retain the core notion of encouraging the user to engage in self-improvement using developing shapes as opposed to numbers or graphs.

TESTING PROTOTYPE AND CUSTOMER FEEDBACK PART 2

The second-round prototyping was conducted online after a new problem statement was defined. This process was invented based on the conclusions drawn from the thematic analysis. The insight gained here was that participants wanted to improve the time they spent on self-improvement. The researcher discovered from this process that what caregivers needed most were support services, as this would allow them to pursue a career path while taking care of LD people. A digital platform was found to be the most effective medium for this outcome.

No.	Name/date tested	Image	Feedback	Improvement
4	Mental self-esteem healing aids		• It is difficult to create a universal design (i.e. a single design that will suit everyone) • Each object looks too personalised; it would be meaningful to someone in particular but not to everyone • Looks very simple (you can create it yourself)	• Add a service platform that can be custom-made for users, e.g. phone call services • Recount my personal story and engage in meaningful conversation to make it feel like counselling • It should be easy like creating a photo album • The product should support time-token services (prototype 6)

No.	Name/date tested	Image	Feedback	Improvement
5	An 'I Cannot stand alone' teacup	I CANNOT STAND WITH OUT YOU Tea mugs design for open conversation for help and support between caregivers and another person	• Feels that a product cannot solve the problems linked to caregiver concerns	• Sell this product to earn money to support the time-token idea • Use of this product must be effected in collaboration with expert counselling.
6	Time token Time-currency platform For caregivers of an LD person		• Likes the key idea of a time currency • It is challenging (balancing demand and supply) • Make it financially sustainable	• Requires much more detail regarding a business plan • How to earn money to manage a non-profit organisation • Combine product numbers 5 and 6 to earn money

Table 5: Testing prototype and feedback cycle 2
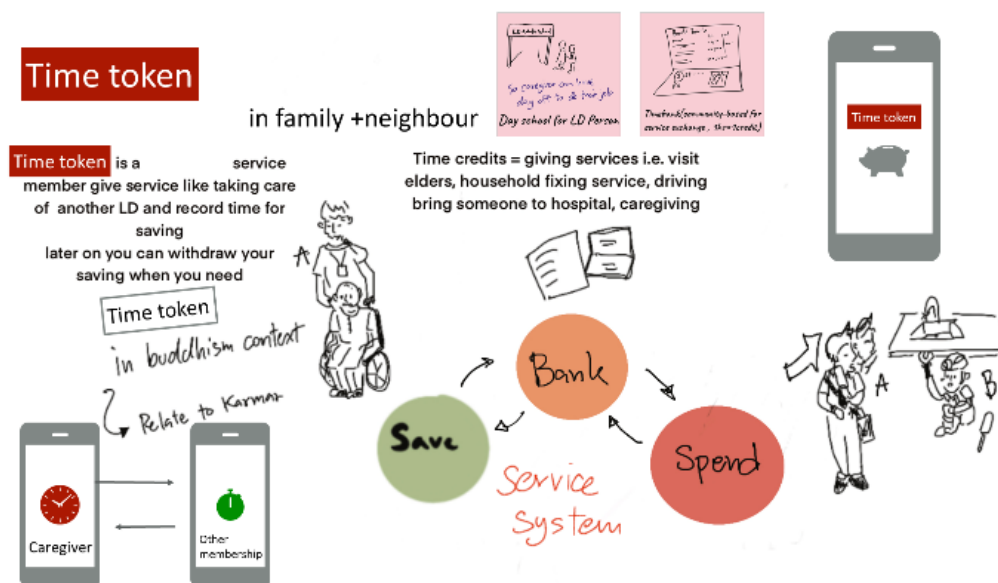
Figure 8: Prototype 6, 'time token'.

REFLECTION ON PROTOTYPING AND TESTING CYCLE 2

The insights the researcher obtained from the second phase of the prototype feedback stage, where there was a requirement for caregiving services outside the home, service design on a digital platform was suitable for responding to the problem regarding a lack of personal time.

All of the participants agreed that the 'time token' had the most potential (see Figure 8). Their major concern was financial and business plans in Thai context. They also agreed on the core ideas of group support, sharing quality time with their LD, and exchanging services within the group. They also expressed concern about membership recruitment within a caregiving group. Additionally, the activities for gaining time currency remained unclear and, as such, requires additional consideration to best fit the needs of caregivers of LD people.

Accordingly, the researcher developed a concept design based on the time token of prototype 6. In the next chapter, the 'Timebank' concept will be explored. Based on the key concept, prototype 6 requires further development to render it more suitable for the target users in a Thai context.

DESIGN AND DEVELOPMENT

The researcher's goal in the designing process was to create a prototype that would provide easy and quick processes for testing the derived concepts. These ideas arose from the development of the research at each systematic step. In this chapter, the design journal presents the models and knowledge acquired by the research at each stage. There were two prototype loops and feedback processes.

The first cycle was conducted following a summary of the literature review. This took place immediately after the online interviews and before the analysis. Prototypes 1–3 were designed to test initial insights gained from existing literature on positive reinforcement, and whether it was effective for managing an LD person's behaviour and a caregiver personal time (see Table 4). The first aspect that the researcher learned from participant comments about the three prototypes was that the reward system worked only for the caregivers themselves. According to feedback about using the reward system of prototype 1, participant concerns were linked to using the reward system with an LD person, which they believed could create conflict rather than being beneficial. The point system measurement applied to children with special needs may thus not be suitable for all patients in this group. The symptoms of a person with special needs syndrome involve different emotional states and may include aggressive behaviour (O'Brien & Pearson, 2004). The participants commented that using rewards and punishments may trigger these symptoms. Therefore, when designing the outcome, the reward system in the final prototype was designed for a caregiver who did not interact with an LD person.

Secondly, the prototype was created based on the data analysis results. Prototypes 4–6 were designed based on the insight that participants wanted to improve the quality of the time they spent on themselves. According to the feedback about the service platform in prototype 6, the researcher learned that this service platform was the most effective mediumT. All the participants stated that this model (an application design) was suitable for responding to their problems, as opposed to a product design only (e.g. prototypes 4 and 5).

The insight obtained from the prototype stage was that caregivers lacked a time management tool in relation to caring for LD people. Accordingly, the outcome will be a service design for responding to the problem statement, i.e. what most caregivers needed was the ability to maintain a career while simultaneously raising children with special needs (see Figure 9).
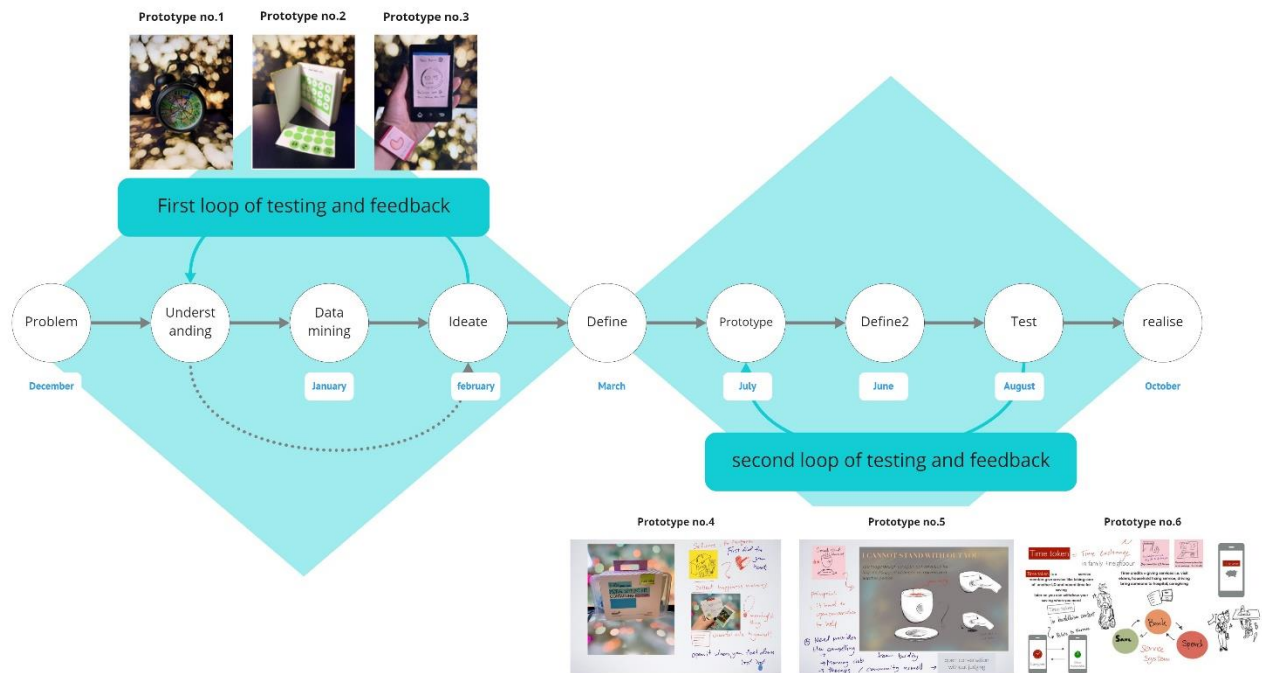
Figure 9: Design journal.

REFLECTION ON DEVELOPMENT OF THE DESIGN

In the design outcome, time was used in the final prototype instead of a point-and-reward system. The prototype was designed for caregivers as a means to address the problem related to a lack of personal quality time. The Timebank system was created for users as a means to help them manage their caregiving time, which, in turn, helped them to better manage their personal time. The researcher aims to design the time token system as transferable between members of the final design service and create activities on a platform that are suitable for user.

DESIGN OUTCOME

The challenges faced by working caregivers, particularly female caregivers, who wish to pursue their careers while concurrently taking care of LD patients, requires a range of design responses. The problem statement derived from prototype cycle 2 indicates the need for caregiving service support. The researcher selected the Timebank model (Dash & Sandhu, 2020) in this regard; however, additional development is required to make the conceptual model fit the Thai context and meet the needs of target users.

WHY SERVICE DESIGN?

Only a small number of organisations work with LD people in Thailand; these include special needs organisations, schools, and healthcare centres for Thai people with autism. As such, LD service support remains lacking. Hill (2013) noted that only 0.5% of autism students received proper treatment in Thailand due to a lack of service support.

To create better service and more effective interaction between service providers and customers, service design is used as a means of formulating and regulating people, infrastructure, communication, and the material components of a service (Lewrick et al., 2018). The operational style of these organisations tends to be that of a service provider rather than taking a product provider approach.

In the current research, service design bases on user-centred methods (Lewrick et al., 2018) which led to the development of solutions via a range of media (i.e. platform and materials). the present study , Service design involved various touchpoints (i.e. social media, applications, staff and poster design), which were integrated into the service system (Stickdorn & Schneider, 2011). Accordingly, service design is likely to meet participant's insight and will thus be suitable for solving the complex problems experienced by caregivers of LD people.

THE CHALLENGES PRESENTED BY THAI CULTURE

Thailand is culturally sensitive about caregiving at home (Subgranon & Lund, 2000). One-third of Thai people in an extended family live with either their parents or with more than one familial generation (Smith, 1973). Most Thais remain accustomed to the bonds of family care (Pinyuchon & Gray, 1997). As such, in Thailand, the home-based caregiving approach remains a mainstream method. Family members are considered best suited to the role of caretakers. Providing sufficient

support services are the first step in encouraging Thai people to consider caregiving services outside the home.

The researcher posits that group caregiving services be initialised by connecting family caregivers with one another. In this regard, research participants prioritised safety and quality of relationship between member who share the common need. Therefore, the service specifically focuses on caregivers of LD people in their own families first. The recruitment aims to verify that people with LDs are cared for by kind and empathetic caregivers, which sets it aside from services elsewhere. As such, caregivers can feel assured about joining these services. Moreover, the proposed design can provide a space for caregivers in which to connect in a meaningful way and support each other.

In conclusion, the service outcome derived from the research is a support group of family caregivers as a needs mechanism that suits Thai culture. Since Buddhism is Thailand's national religion, the researcher proposes a mechanism through which time is harmonised; this coincides with the beliefs among Thai people who may remain sensitive about using money in exchange for their LD family member being cared for. Some of Thai caregivers believe in *boonkun* (gratitude), one of the laws of Karma in Buddhism, and, accordingly, feel that family caregivers must try their best to take care of family members with an LD (Subgranon & Lund, 2000).

In the long run, however, *boonkun* causes primary caregivers to feel that they have been treated unfairly; this is due to the nature of '*boonkun*'being unmeasurable and unequal (i.e., the relationship between siblinghood/parenthood is not equal based on the law of *boonkun*).

In conclusion, the service outcome is a support group of family caregivers as a needs mechanism that suits Thai culture. This service offers a time currency exchange based on customer insights within the Thai context and will be discussed further in the next chapter.

WHAT IS TIME CURRENCY?

Caregiving for people with LDs is a long-term service. It is important to have a mechanism that will keep service users motivated to achieve their lifelong goals (Weinschenk, 2011). It was found that many reward systems, e.g. points and rewards, were useful and motivating over a short period (Ferster, 1964; O'leary & Becker, 1967). However, such a service does not meet the needs of the current research's target user. It is difficult to value the invaluable caregiving services provided by family members. Thus, time was considered a medium for exchange within the context of caregiving services.

Service is part of the sharing economy. The concept of a time token is derived from the Timebanking idea, which was introduced in England nearly two decades ago (Seyfang, 2004). Time tokens aim to create engagement, which indicates the value of activities within services (Dash & Sandhu, 2020). Members can earn time credits by offering services to other members when they have free time. Originally, Timebanking was a type of currency and one of its core rules was providing one hour of service to another member and receiving one-time credit in return. This rule was based on the five core values[2] of the Timebank system, which determined that everyone's time was equal. Timebank is a global organisation that provides a wide range of services at a one-on-one (person-to-person) level, such as home-repair, driving services and services delivered by an individual to a community. However, Shih, Bellotti, Han, and Carroll (2015) noted the challenging nature of equalising time for a wider range of services through Timebanking.

The service design outcome in the current research thus applied the core ideas of timebank to suit its target users. This was achieved by focusing solely on the members of a small group of caregivers of LD people in Thailand.

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[2] **The five core values are asset (i.e. everyone has the ability to give and receive), redefining work (i.e. the value of some work is beyond money (e.g. building community), reciprocity (i.e. helping work to be more effective as a two-way, give-and-receive activity), social networks, and respect.**

HOW THE SERVICE WORKS

Figure 10: How the Muta service works.

The Muta application was designed as a platform for recording time exchange transactions. The Muta service acts like a timebank. Members can earn time credits when they join volunteer activities in their free time. Later, they can spend their time credits from a savings account as needed. The time credits can be used in a co-working space. Time tokens are also transferable; members can voluntarily invite family members or friends to collaborate in caregiving LDs activities and transfer time tokens to another savings account or between different members' savings accounts. The researcher chose an application platform is because it is scalable, can be operated easily using a mobile device and can deliver the most benefits to users.

DESIGN DEVELOPMENT

USER FLOW AND WIREFRAMES

This process started using user flow diagrams, which were employed to define the pages that had to be created for the application. The user flow allowed the researcher to gain an overall view of the user experience when using services. Following on, user flow led to the process in which screen menus within the application were defined (see Figure 16).

The service blueprint (see Figure 17) illustrates the interoperability between user actions, the application screen and the support system that runs the application. The blueprint demonstrates user activities by illustrating each step systematically from the outset. It is divided into three parts: pre-service, during-service, and post-service.

User flow diagram
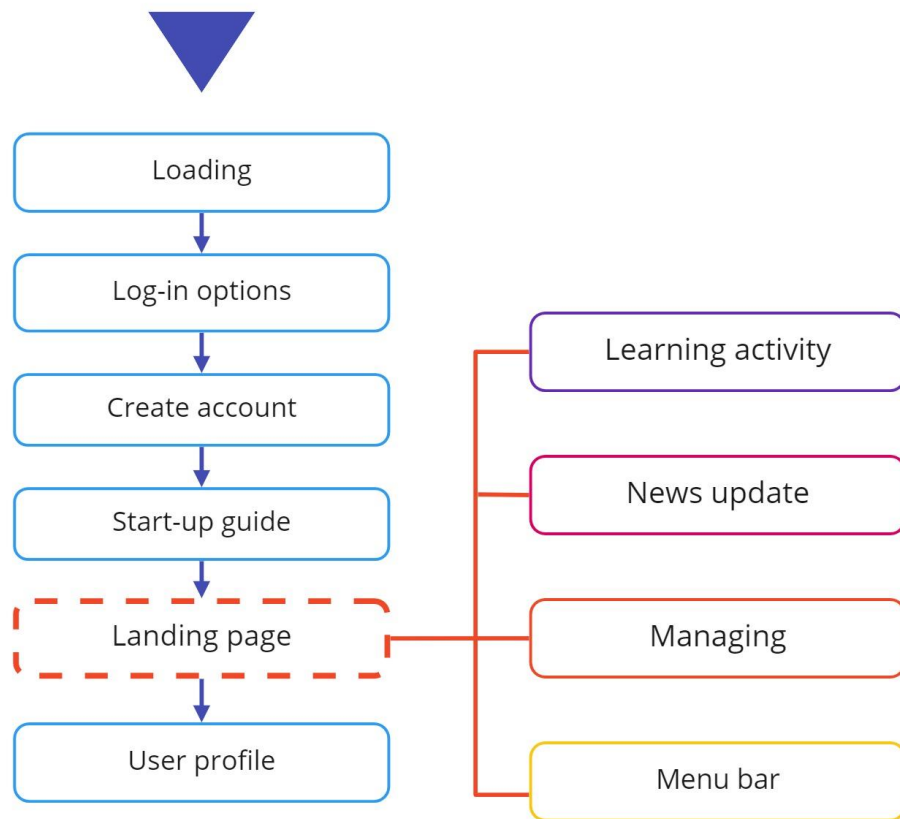
Figure 11: User flow.

SERVICE BLUEPRINT

The service design blueprint (see Appendix 6) was selected to illustrate an overview of Muta services. The blueprint shows three main service sections differentiated by colour: 1) pre-service (Appendix 6, dark purple column); 2) during service (bright violet column); 3) after service (red column). The application is part of the support service, which serves as a crucial touchpoint of Muta.

First, the pre-service aspect concerns user activities prior to engaging inthe design services (Appendix 6). The screen loads an advertisement delivered via social media, searches for information, and downloads applications. These steps helped the researcher to clarify service touchpoints and consider workflow. Second, the during-service section shows how to use the Muta application and explains the steps for accessing physical spaces linked to Muta co-work, as well as creative spaces. The final step is post-service, which concerns the recruitment of new users and user feedback.

This service blueprint was used to revise the service touchpoints and user experience. The researcher recognised that selected functions, e.g. time credit loans, had to be removed. Moreover, the services needed to provide the exact conditions in which users would be volunteering to work alongside the support group to earn time credits (i.e. before using the co-working space), rather than indicating the number of free hours first. they needed to work to receive hour credits.

Figure 12: A paper mock-up used for deriving feedback from participants.

Subsequently, the researcher developed and adjusted the key ideas taken from the service blueprint to create the format for the application screens in the form of a paper mock-up to test the initial main page ideas of the design Apps (see Figure 6).

LO-FI WIREFRAME

During the final design phase, the researcher drafted a lo-fi wireframe using Miro (v.2020), the online whiteboard programme, to define the overall application flow chart. Following on, the prototype was created using PowerPoint (v.2019). The researcher aligned all the screens created as lo-fi wireframes (see Figure 7) and animated each graphic element included in the application to review the user flow for each screen. Additionally, a newsfeed page was merged into the offer board to reduce confusion. Subsequently, a wireframe was developed, and the main menus and functions were simplified into hi-fi frames (see Figure 8). The concluding step was creating the final screens of the Muta application with a range of different services (see Figure 9).
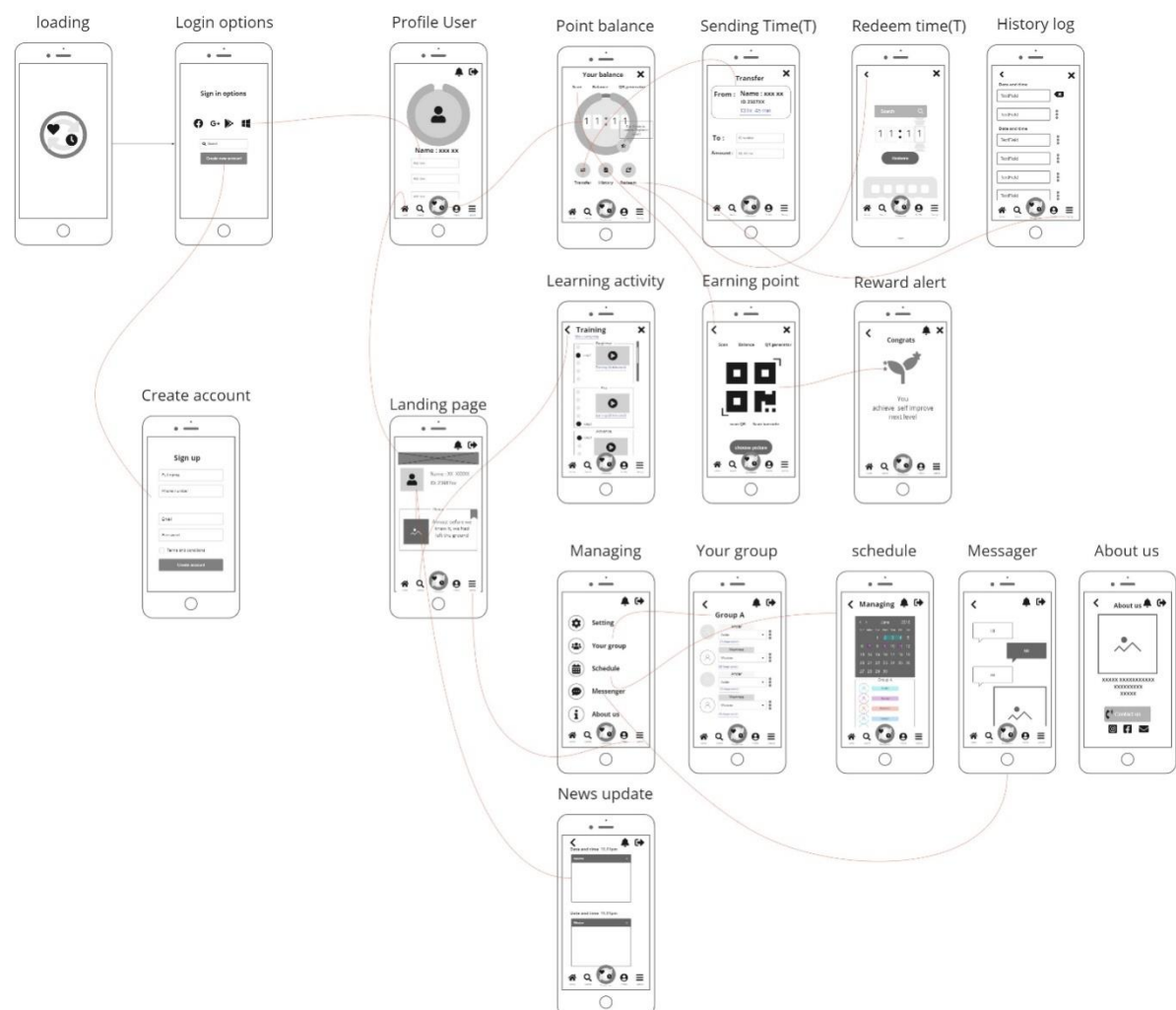
Figure 13: Lo-Fi wireframe designs for the Muta application with a range of different services.

loading   Login options   Sign up page   Point balance   Transfer Time(T)   History log

Landing page   Offer board   Offer board notification   QR code   Check out notification   Reward alert

Groups

Setting
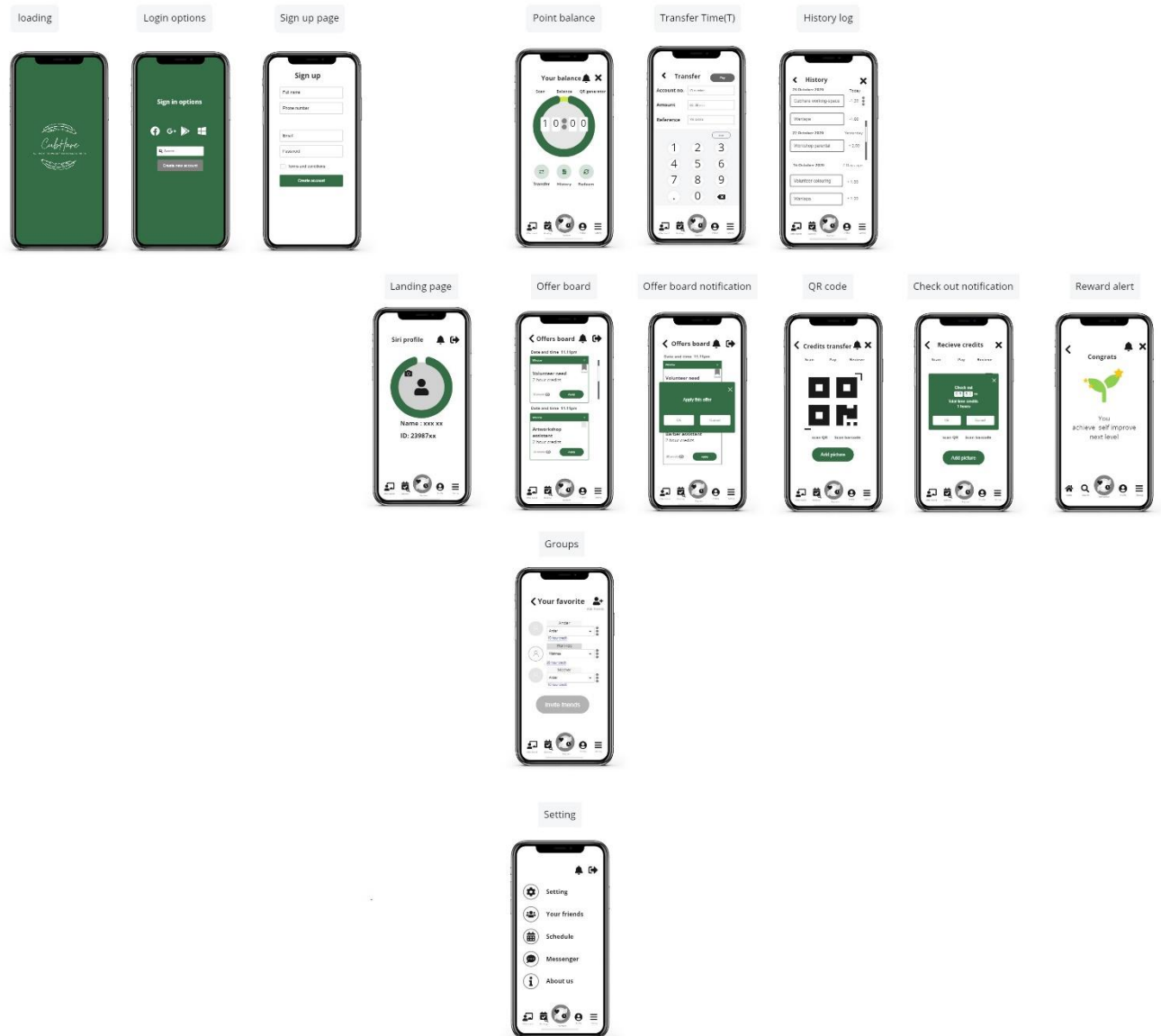
Figure 14: The hi-fi wireframe designs for the Muta application with a range of different services.

Figure 15: The final Muta application prototype.

MUTA SERVICES

Figure 17: The term "Mudita" in Thai.

Figure 16 Logo on Products

"Muta" was derived from *Mudita*, which refers to a Buddhist mindset (see Figure 11). It is related to the pleasure a parent experiences when observing their growing child's accomplishments and successes. Muta's members are a group of family members of LD people who collaboratively share the experiences of caring for people with learning disabilities, using the medium of time in exchange for caregiving advice. Muta services employs a volunteer service system using time currency as a mechanism. It is used to encourage members to contribute their time as a medium in exchange for services within the community.

Figure 18: Key concept of Muta services.

The key value activity of Muta services is to function as a centre for providing caregiving services. The purpose of the application is to connect individual caregivers and to provide three specific services to assist them: grouping, managing, and providing a co-working space.

MANAGING: Muta aims to supervise the quality of caregiving services in a bid to help individual caregivers improve their quality of life and to succeed in their personal life-path while taking care of people with special needs. The service also aims to create a safe community that will facilitate the care of caregivers' loved ones. aim of the application established the centralised management of people as a means to connect them with one another, record transactions, and provide activities, such as workshops and group meetings. Time tokens were incorporated into the system as a means to manage the long-term quality of services.

Grouping: The Muta platform assists individual caregivers in establish a caregiving team. Grouping activities aim to encourage caregivers to exchange caregiving skills and knowledge and to meet people who face similar situations to their own.

Another purpose of grouping is for caregivers to support one another through empowerment (Banach, Iudice, Conway, & Couse, 2010). The power of integration also encourages caregivers who have recently joined the support group to experience a sense of belonging in such a unique and understanding community. The group also provides collaborative support in the form of a creative space (see Figure 13).

Figure 19: The creative space and support group services

Creative space: Muta helps to facilitate a physical space that serves as a venue for caregivers of LD people in which to experience meaningful connection and support one another.

These services are operated based on the rules of timebank, through which time is exchanged with special needs child support facilities. Muta members must earn time credits by attending caregiving

group activities in the creative space. They can choose to join any workshop that matches their personal interests, e.g. an art therapy workshop, a ceramics handicraft workshop, or a weaving workshop. These workshop activities offer them opportunities to learn and spend quality time among other caregivers. Members can spend their collected time credits whenever they need to use the co-working space (see Figure 13).

DISCUSSION

The research question addressed the need to find a way to assist Thai caregivers looking after an LD family member. Existing literature states that positive reinforcement (Ferster, 1964) can encourage positive behaviours. However, initial insights after conducting online interviews did not support this notion. According to feedback cycle 1, concerns about a reward system indicated it may give rise to conflict between a caregiver and an LD person. Accordingly, what the researcher learned from the data-collecting process (based on the interviews conducted) differed from the findings noted in the literature review. The results were derived from primary data collection, during which real users were interviewed. The researcher found this process to have been invaluable because it provided participant opinions that reflected their true feelings and personal caregiving experiences. In addition to the goals of creating designs to improve Thai caregivers' quality of life, this research also serves as a medium for conveying the challenges caregivers face. It is crucial that caregivers recognise that they are not alone and can find support from others with the same experiences.

The research revealed caregivers' most challenging problem to be creating a balance between their career and their caregiving role. Caregivers have to be able to maintain the expectations they have for their own lives and maintain healthy self-esteem. The design outcome of this study offers an alternative solution for managing the problems caregivers experience by providing a physical space and a support group of caregivers working with learning-disabled people. Caregivers sometimes need advice and support related to the challenges of caring for LD people. To manage problems sustainably and effectively, the researcher recommends that workforce law and humane workplace policies become actively involved in this context (Lewis et al., 2000). Muta requires members to collaboratively exchange caregiving experiences as part of the group mechanism. Accordingly, it is essential that full-time employees who also serve as caregivers be supported by workforce law and workplace policies, and allow them to adopt flexible working hours to support a healthy work–life balance. Policies and law can help to sustainably address this problem in the future.

RESEARCH LIMITATIONS

The challenges of this research were searching for a solution that would solve the problem at hand using service design within the allotted time frame. Moreover, the research sample size was limited. The number of participants could not represent all possible Thai caregiving challenges. For a broader and deeper understanding of the issues experienced by caregivers, future research should expand the sample group. Additionally, a more comprehensive group of participants, who similarly assume long-term caregiving responsibilities should be included, e.g. male caregivers who are responsible for taking care of female LD patients.

In the context of the Covid-19 situation, which has been in effect since late 2019 and currently continues, the research's co-design method (participant participation tool) was limited. The pandemic affected the number of participants that could be included in the research. As a result, the co-design section had to be modified. It was changed from face to face to online feedback meetings. The researcher acknowledges that to achieve better service design development, the relevant stakeholders should be involved in the co-design discussion, as was originally planned.

FUTURE RESEARCH

Future research related to service design should emphasise stakeholder insights. Due to the time constraints of the present research and the Covid-19 situation, the co-design section had to be adjusted to online feedback meetings. The researcher recommends that further service design research adopt a co-design method to help develop better service design. This approach requires collaboration among stakeholders, such as governmental non-governmental organisations (NGOs), investors, and healthcare professionals. If stakeholders can co-create and develop a prototype alongside researchers, broader perspectives of problems can be introduced alongside additional practical solutions. Moreover, organisational stakeholders can provide resources and funding for practically realising the Muta business model.

The Muta service design offers an alternative solution to family caregivers to maintain their career while simultaneously caring for LD people. Muta is a volunteer service that involves family caregivers who support one another through the use of time as a medium of exchange within the Muta community. The service design provides a co-working space and a caregiver support group.

Time credits are a key element of the design, as the research discovered aspects other than money that required recognition, such as building a community and caring for family members. Muta members will receive a one-hour credit per one hour they contribute to any volunteer activity involving LD people. These rules were adapted from the concept of time equality within the timebanking method (Seyfang, 2004). Caregivers can subsequently spend their time credits in a co-working space as required.

The final service design outcome was developed through a product development cycle of rapid prototyping and testing using a design thinking methodology. This was a feasible approach that offered invaluable and desirable outcomes that can assist caregivers to support one another sustainably.

Muta offers caregivers an opportunity to be supported, improve their quality of life, and to achieve success in their chosen career path. It advocates for the value of their time, based on the belief that time is valuable and everyone's time is of equal value.

CONCLUSION

This research examined the feasibility of creating design outcomes by employing an empathic approach to the target user. A design thinking methodology (a user-centred design approach) was employed in this regard. This methodology is considered feasible and offers valuable and desirable activities.

The population of people with LDs is increasing annually in Thailand (Plubrukarn et al., 2005), along with the need for caregivers who can care for them. This problem affects both individuals, communities, and society as a whole.

A design thinking methodology is a process for developing designs based on customer perspectives. Its methods, such as ideation, refining, prototyping and testing are back-and-forth steps that shape an in-depth understanding of target consumers (Sanders & Stappers, 2014). Emphasis on customers is a core aspect of creating effective product innovation and service design outcomes (Kouprie & Visser, 2009). This level of understanding cannot be achieved by traditional methods (e.g. a literature review). Additionally, the methods of this approach identify key value propositions. The researcher appreciated the value of the design thinking process and used her skills in this context to help her understand the problems of caregivers from their perspectives. The method helped to shape the outcome delivery process, which supported her design in terms of meeting the needs of users through the product development cycle. In addition, self-reflection implemented by the researcher in each of the research processes helped to clarify applicable knowledge for future studies.

The Muta services design outcome is a suggested solution for responding to the problems of Thai caregivers caring for LD people. Muta is a time-based currency platform for caregivers of people with LDs. The platform serves as a central hub for the management of activities and membership. The primary actions facilitated by the platform are managing transactions, caregiving and creating opportunities for caregivers to connect with other caregivers.

Muta represents a service design that incorporates group support for employed caregivers who also care for an LD family member. This is, however, only one part of a solution required for a complex problem. The researcher suggests that additional services are needed to support caregivers in maintaining their employment positions while taking care of the people with special needs in a Thai

context. In this regard, the cooperation of government, as well as changes to company policy and the law are required to address problems more effectively and in a sustainable manner.

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APPENDIX

APPENDIX 1: PARTICIPANT INFORMATION SHEET

PARTICIPANT INFORMATION SHEET

Product and service design to assist caregivers of adults with learning disabilities

An invitation

Hello, Sawadeeka, my name is Onwara Khongpaiboon. I would like to invite you to be a significant part of my research project about adult family caregivers caring for family members with a learning disability (LD). I am a postgraduate Master of Design student at Auckland University of Technology (AUT), New Zealand. As part of my research, I aim to interview individuals with caregiving experience and the challenges they face in a Thai context.

Before you decide whether to take part, it is important that you understand why the research is being conducted and what participating will involve. If you have any questions, please do not hesitate to ask me. Talk to others about the study if you wish. Your participation in and support for this study will be greatly appreciated and represents significant content value.

What is the purpose of this research?
The purpose of this study is to understand the challenges caregivers experience and to investigate a potential design solution for those caring for individuals with an LD as it relates to daily tasks. The research outcomes may result in a mobile application or a printed, physical graphic design product. The final research output will rely on the results of an analysis based on data gained from interviews and a co-design workshop.

How was I identified and why am I being invited to participate in this research?
You received this invitation because of your personal experience of caring for adults with LD and because of your familial relationship with them (sibling/parent).

How do I agree to participate in this research?

Your participation in this research is voluntary and will neither advantage nor disadvantage you. You can withdraw from the study at any time. If you choose to withdraw from the study, you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing for its continued use. Note, however, that once the findings have been published, removal of your data may not be possible.

What will happen in this research?
If necessary, follow-up email/telephone communications or face-to-face meetings will be initiated by the researcher for clarifying any understanding of participant inputs, or to obtain further information from to complete the research project.

How will my privacy be protected?
All data collected by the researcher will only be seen by the researcher and her supervisors. Your identity will also be kept confidential using pseudonyms. Participation is completely voluntary. I emphasise that if participants are uncomfortable with what they are being asked, there will be no expectation that they answer such questions.

What are the costs of participating in this research?
There is no monetary cost to participants who are involved in this study. Participation in this study will, however, require an investment of around 30 minutes to 1 hour of your valuable time, which will be reimbursed with a Koha (i.e. is a New Zealand Māori custom which can be translated as gift, present, offering, donation or contribution.) to thank you for your cooperation.

Will I receive feedback about the results of this research?
A summary of the research findings will be offered to you, should you wish to receive one.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to my supervisor, Dr Amabel Hunting, email: amabel.huntingl@aut.ac.nz Tel: +64 9 921 9999 ext. L8762 Concerns regarding research conduct should be notified to the Executive Secretary of AUTEC, Kate O'Connor, email: ethics@aut.ac.nz, 921 9999 ext. 6038.

Researcher Contact Details:

Onwara Khongpaiboon
Postgraduate student, School of Art and Design, Auckland University of Technology (AUT)

Email: Onwarakpb@gmail.com

Telephone: +66 86 868 5054 (TH)

+64 21 085 85328 (NZ)

Online interview questions

General question about caregiving involving a learning disability
What does the term 'learning disability' mean to you?

Basic information history
Who in your family has a learning disability?
How long have they had this learning disability?
How would you define your relationship with this family member?
How independent are they?
What are the factors that have an impact on their level of independence?

Challenges of being a caregiver
What challenges do you as a caregiver of someone with a learning disability face? What are your pain points?
Are there tools/things that will help to make your caregiving role easier?

Goals
What would you like to achieve (i.e. greater independence, better communication, etc.)?
What does the prospect of your LD family member being more independent mean to you?
What does a person with an LD being able to communicate better represent to you?

Positive reinforcement

From your experience, what has worked for you in terms of changing the behaviour of people with LD (e.g. positive reinforcement, negative punishment etc.)?
What types of strategies do you employ to help them change their behaviour?
Do you prefer positive or negative strategies in terms of punishment or rewards', etc.?

Tools
What tools have you used while caring for your loved one?
Have you used any type of technology?
Do you think doing so will help you?
Would you prefer to use physical tools?

Cost
Are you only interested in tools that are freely available?
Would you be willing to pay for service or application, and if so, how much would you be willing to pay?

Online interview protocol

The online interviews will be audio-recorded to facilitate data collection and for transcribing participants' responses, which will be used for interpretation and discovering patterns. Only the researcher and project supervisors will have access to these data. The information will be kept in a safe place on the AUT premises and will be destroyed once this master's degree is completed. Your participation in this interview is voluntary and you have the right to withdraw at any time without any repercussions. Please make sure that you have recorded an oral consent form. Once you have done so, please send a copy of this video to me and keep a copy for yourself. Thank you for agreeing to be a part of this study.

The interview will last as long as our conversation continues but will not exceed one hour. As the structured interview suggests, I have prepared the questions that will be asked in advance. This will help to keep the conversation focused on the topic. You are welcome to ask for more details and examples from me if you have any doubts about answering any of the questions.

Safety recording screen and oral consent protocol

Since the interview will be conducted online, the process of signing the consent letter and acceptance via a digital PDF file may be too complicated for participants. Therefore, the researcher asked interviewees to provide consent orally by recording an audio and visual recording (without identifying the participant's face and body parts) as evidence of consent to participate in the research.

Photography protocol

The user testing focus group will be photographed when participants interact with the potential design prototype. The researcher will ensure that only participants' hands are photographed and that no faces are included in photographs to protect the identities of participants.

All photographs will be kept confidential. All information and applications will be used for research and publication in academic journals only and will not be used for commercial purposes.

Consent Form – Online interview

Project title: Product and service design to assist caregivers of adults with learning disabilities

Researcher: Onwara khongpaiboon

- ○ I have read and understood the information provided about this research project in the Information Sheet dated 1 October 2020
- ○ I have had an opportunity to ask questions and to have them answered.
- ○ I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential.
- ○ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- ○ I understand that notes will be taken during the focus group/ Online interview, and data gathered. I CONSENT to this data being used within this Co-Design for the researcher.
- ○ I understand that if I withdraw from the study then, while it may not be possible to destroy all records of the focus group discussion of which I was part, I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- ○ I understand that any data collected during this focus group online interview will be given to the researcher and will be securely and confidentially stored at AUT and be scanned in external hard drive separately. The original will be shredded once the researcher submits the final result to committee.
- ○ I agree and give my CONSENT to take part in this research.
- ○ I wish to receive a summary of the research findings (please tick one): YesO   NoO

Participant's signature :   ……………………………………………………………………………………………

Participant's name :   ………………………………………………………………………………………

Participant's Contact Details (if appropriate)

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Date :

Approved by the Auckland University of Technology Ethics Committee on

Auckland University of Technology Ethics Committee (AUTEC)

EA1

APPLICATION FOR ETHICS APPROVAL BY AUTEC

For AUTEC Secretariat Use only

_____/_____

Please print this application single sided in greyscale and do not staple. Once this application has been completed and signed, please read the notes at the end of the form for information about submission of the application for review.

NOTES ABOUT COMPLETION

❖ Ethics review is a community review of the ethical aspects of a research proposal. Responses should use clear everyday language with appropriate definitions being provided should the use of technical or academic jargon be necessary.

❖ The AUTEC Secretariat and your AUTEC Faculty Representative are able to provide you with assistance and guidance with the completion of this application which may help expedite the granting of ethics approval.

❖ The information in this application needs to be clearly stated and to contain sufficient details to enable AUTEC to make an informed decision about the ethical quality of the research. Responses that do not provide sufficient information may delay approval because further information will be sought. Overly long responses may also delay approval when unnecessary information hinders clarity. In general, each response should be around 100 words.

❖ AUTEC reserves the right not to consider applications that are incomplete or inadequate. Please do not alter the formatting or numbering of the form in any way or remove any of the help text.

❖ Comprehensive information about ethics approval and what may be required is available online at http://aut.ac.nz/researchethics

❖ The information provided in this application will be used for the purposes of granting ethics approval. It may also be provided to the Graduate Research School, the Research and Innovation Office, or the University's insurers for purposes relating to AUT's interests.

❖ The Form is focussed around AUTEC's ethical principles, which are in accordance with the *Guidelines for the approval of ethics committees* in New Zealand.

To respond to a question, please place your cursor in the space following the question and its notes and begin typing.

A.   *Project Information*

A.1.   What is the title of the research?

If you will be using a different title in documents to that being used as your working title, please provide both, clearly indicating which title will be used for what purpose.

Product and service design to assist caregivers of adults with learning disabilities

A.2.   Is this application for research that is being undertaken in stages?   ☒ Yes ☐ No

If the answer is 'Yes' please answer A.2.1 and the following sections, otherwise please answer A.3 and continue from there.

A.2.1.   Does this application cover all the stages of the research?   ☒ Yes ☐ No

If the answer is 'No' please provide details here of which stages are being covered by this application, otherwise please answer A.3 and continue from there.

This application covers the data collection in an in-depth interview and participant co-design phase.

A.3.   Who is the applicant?

When the research is part of the requirements for a qualification at AUT, then the applicant is always the primary supervisor. Otherwise, the applicant is the researcher primarily responsible for the research, to whom all enquiries and correspondence relating to this application will be addressed.

Amabel Hunting

A.4.   Further information about the applicant.

A.4.1.   In which faculty, directorate, or research centre is the applicant located?

Design and Creative Technologies

A.4.2.   What are the applicant's qualifications?

PhD

A.4.3.   What is the applicant's email address?

An email address at which the applicant can be contacted is essential.

amabel.hunting@aut.ac.nz

A.5.   Research Instruments

A.5.1.   Which of the following does the research use:

☒ *a written or electronic questionnaire or survey*   ☒ *focus groups*   ☒ *interviews*
☐ *observation*   ☐ *participant observation*   ☐ *ethnography*   ☐ *photographs*
☐ *videos*   ☐ *other visual recordings*   ☒ *a creative, artistic, or design process*
☐ *performance tests*
☐ *some other research instrument (please specify)*

Please attach to this application form all the relevant research protocols. These may include: Indicative questions (for interviews or focus groups); a copy of the finalised questionnaire or survey in the format that it will be presented to participants (for a written or electronic questionnaire or survey); a protocol indicating how the data will be recorded (e.g. audiotape, videotape, note-taking) for focus groups or interviews (Note: when focus groups are being recorded, you will need to make sure there is provision for explicit consent on the Consent Form and attach to this Application Form examples of indicative questions or the full focus group schedule. Please note that there are specific confidentiality issues associated with focus groups that need to be addressed); a copy of the observation protocol that will be used (for observations); full information about the use of visual recordings of any sort, including appropriate protocols and consent processes; protocols for any creative, artistic, or design process; a copy of the protocols for the instruments and the instruments that will be used to record results if you will use some other research instrument.

A.5.2.   Who will be transcribing or recording the data?

If someone other than the applicant or primary researcher will be transcribing the interview or focus group records or taking the notes, you will need to provide a confidentiality agreement with this Application Form.

Onwara khongpaiboon

A.6.   Please provide a brief plain English summary of the research (300 words maximum).

This research project aims to investigate and design an alternative solution for caregivers who take care of adults with learning disabilities in day to day tasks. The challenge of adults with Learning disabled is the ability to set goals, build relationships and communicate with others as part of their daily routines (Chapman, Lacey, & Jervis, 2018). A lot of learning disabled adults cannot obtain a job or live independently, with the majority of them in adults having to live in their childhood home (Stevens, 2004). Subsequently, learning disabled people need a caregiver to assist them (Cortiella, 2011). However, these people might want to have a level of independence as adults, which can become a challenge for the caregiver to maintain a healthy relationship with the Learning disabled adult (Chatwattananon, 2011). The purpose of this research is to investigate family members who are caring for learning disabled people and design solutions that could assist them and enhance the relationship with their family caregivers.

In Thailand, the majority of caregiving is provided by family members, with less support from health care organisations. The learning disability conditions in Thailand have a stronger collectivism approach due to this cultural background. The researcher is Thai and has an adult family member with a learning disability so I am personally invested in doing this research to design solutions that could benefit other caregivers. This research aims to collaborate with Arunothai's project, a centre of family caregivers in Bangkok, Thailand. Neither myself or my family have used this organisation before. This organisation will give access to potential caregivers and, through user insights, I aim to discover ways that family members could be further supported.

The final research output will be dependent on the result of the data analysis of the interview and focus group (using a co-design method). It is a form of focus group where I can test potential design concepts with participants. The potential research outcomes may include an application on mobile phone or a physical outcome, such as a graphics design or physical prototype.

The researcher will recruit participants by personal contact and via networking of Arunothai organization for an online interview to understand their user needs. A co-design workshop will then be held in Thailand at their office will the aim of building and testing a potential design outcome. Co-design process enables participants to be actively part of the design process and ensure a more effective solution to support these end-users.

A.7.   Additional Research Information

A.7.1.   Is this research an intervention study?   ☐ Yes ☒ No

For research in general, what is the difference between intervention, interaction, and observation? Intervention includes both physical procedures by which data are gathered and manipulations of the participant or participant's environment that are performed for research purposes. Interaction includes communication or interpersonal contact between the investigator and participant that are performed for research purposes. Observation is neither an intervention nor an interaction. (cf https://www.gvsu.edu/hrrc/faq-definitions-35.htm).

Within health and disability research, 'intervention study' has the meaning given to it by the National Ethics Advisory Council's Ethical Guidelines for Intervention Studies; namely, a study in which the investigator controls and studies the intervention(s) provided to participants for the purpose of adding to knowledge of the health effects of the intervention(s). The term 'intervention study' is often used interchangeably with the terms 'experimental study' and 'clinical trial' (s.24 Standard Operating Procedures for Health and Disability Ethics Committees).

A.7.2.   Is this Health and Disability Research?   ☐ Yes ☒ No

Health and disability research is research that aims to generate knowledge for the purpose of improving health and independence outcomes (s.21 Standard Operating Procedures for Health and Disability Ethics Committees).

A.7.3.   Does this research involve people in their capacity as consumers of health or disability support services, or in their capacity as relatives or caregivers of consumers of health or disability support services, or as volunteers in clinical trials (including, for the avoidance of doubt, bioequivalence and bioavailability studies)?   ☒ Yes ☐ No

B.   *The Ethical Principle of Research Adequacy*

AUTEC recognises that different research paradigms may inform the conception and design of projects. It adopts the following minimal criteria of adequacy: the project must have clear research goals; its design must make it possible to meet those goals; and the project should not be trivial but should potentially contribute to the advancement of knowledge to an extent that warrants any cost or risk to participants.

B.1.   Is the applicant the person doing most of the research (the primary researcher)?   ☐ Yes ☒ No

If the answer is 'No' please answer B.1.1 and the following sections, otherwise please answer B.2 and continue from there.

B.1.1.   What is the name of the primary researcher if it is someone other than the applicant?

Onwara khongpaiboon

B.1.2.   What are the primary researcher's completed qualifications?

Bachelor of Design

B.1.3.   What is the primary researcher's email address?

An email address at which the primary researcher can be contacted is essential.

Onwarakpb@gmail.com

B.1.4.   At which telephone numbers can the primary researcher be contacted during the day?

+64 21085 85328

B.2.   Is the primary researcher

☐ *an AUT staff member*   ☒ *an AUT student*

If the primary researcher is an AUT staff member, please answer B.2.1 and the following sections, otherwise please answer B.3 and continue from there.

B.2.1.   In which faculty, directorate, or research centre is the primary researcher employed?

If the response to this section is the same as that already given to section A.4.1 above, please skip this section and go to section B.2.2.

B.2.2.   In which school or department is the primary researcher employed?

B.3.   When the primary researcher is a student:

B.3.1.   What is their Student ID Number?

18019036

B.3.2.   **In which faculty are they enrolled?**

Design

B.3.3.   **In which school, department, or Research Centre are they enrolled?**

School of Art and Design, Auckland University of Technology

B.4.   **What is the primary researcher's experience or expertise in this area of research?**

Where the primary researcher is a student at AUT, please identify the applicant's experience or expertise in this area of research as well.

The primary researcher has experience in research design method having completed a Bachelors degree in Industrial design at King Mongkut's Institute of Technology of Ladkrabang(KMITL) in Thailand. She has experience as a Junior Service Designer working with hospital and banking services in Thailand. She is also a sibling of an adult with learning disabled (LD). Her direct experience with her brother in her role as a family caregiver has been a driver for this project and she has connections with other families and the ability to empathise with the challenges of being a caregiver of a LD person.

B.5.   **Who is in charge of data collection?**

The primary researcher, Onwara khongpaiboon

B.6.   **Who will interact with the participants?**

The primary researcher, Onwara khongpaiboon

B.7.   **Is this research being undertaken as part of a qualification?**   ☒ Yes ☐ No

If the answer is 'Yes' please answer B.7.1 and the following sections, otherwise please answer B.8 and continue from there.

B.7.1.   **What is the name of the qualification?**

Master of Design

B.7.2.   **In which institution will the qualification be undertaken?**

Auckland University of Technology

B.8.   **Details of Other Researchers or Investigators**

B.8.1.   **Will any other people be involved as researchers, co- investigators, or supervisors?**   ☒ Yes ☐ No

If the answer is 'Yes' please answer B.8.1.1 and the following sections, otherwise please answer B.8.2 and continue from there.

B.8.1.1   **What are the names of any other people involved as researchers, investigators, or supervisors?**

Dr. Yingzi Xu

B.8.1.2   **Where do they work?**

Auckland University of Technology

B.8.1.3   **What will their roles be in the research?**

Secondary supervisor

B.8.1.4   **What are their completed qualifications?**

Doctor of Business Administration, Maastricht School of Management, the Netherlands

Master of Business Administration, Maastricht School of Management, the Netherlands

Bachelor of Science (Electronic Engineering), University of Electronic Science and Technology, China

B.8.2.   **Will any research organisation or other organisation be involved in the research?**   ☐ Yes ☒ No

If the answer is 'Yes' please answer B.8.2.1 and the following sections, otherwise please answer B.9 and continue from there.

B.8.2.1   **What are the names of the organisations?**

N/A

B.8.2.2   **Where are they located?**

N/A

B.8.2.3   **What will their roles be in the research?**

N/A

B.9.   Why are you doing this research and what is its aim and background?

Please provide the key outcomes or research questions and an academic rationale with sufficient information, including relevant references, to place the project in perspective and to allow the project's significance to be assessed.

Cortiella (2011) showed that two in ten children are affected by Learning Disability (LD). A learning disability is defined as a life-long neurobiological disorder that affects the manner in which individuals with potentially normal or above average intelligence select, retain and express information (Cortiella, 2011). Therefore, adults with LD need support for their entire life. However, support needs varied depending on the amount of the involvement of caregivers. The need for support from caregivers may vary depending on the individual. It is also difficult for adults with LD to live on their own. The main problems these Learning disable adults face is maintaining personal relationships, setting goals, and navigating daily tasks (Chapman, Lacey, & Jervis, 2018).

Fox, Vaughn, Wyatte, & Dunlap (2002) state that caring for a learning disabled person was challenging for families effecting their relationships, physical circumstances, social network's and daily activities. This research project aims to develop a tool or process to assist a caregiver who is taking care of family member's adult with learning disability in day-to-day task The research will use practice-based methodology (Crouch & Pearce , 2012). There are three main processes 1. theorising, 2. reflecting, 3. designing (Walker & Giard, 2013). A qualitative methodology was chosen in the first phase of the research to gather data and refine the research question. Expert interview will be conduct online via Skype platform to gathering qualitative data.

The second phase will be using design thinking methodology (Lewrick, Link, & Leifer, 2018), which is used to analyse data from a literature review and an in-depth interview method (Martin & Hanington, 2012). This third phase of research includes a Co-design stage to gain insight of caregivers who are caring for people with LD. The co-design will be expected to gather caregivers voice also to prototype the design outcome out of user-centred criteria.

The researcher has her own experience as a primary caregiver of her brother who was diagnosed with a learning disabilities. She comes from Thailand, which is the environment of the research sitesso is familiar with the cultural context. The researcher has a passion about this project that aims to help people like her brother andimprove the quality of caring for a learning disabled person in a Thai context.

This outcome of this research may result in design an App (i.e. smart phone application), will be created by the participants with the researcher. Also, it requires the practical skills of user experience and user interface design to create the application.

B.10.   What are the potential benefits of this research to the participants, the researcher, and the wider community?

The researcher aims to improve her understanding of need of end-user who she designing for. Participants with LD may feel empowered taking part in co-design that will have a positive impact on their future care for their family member and to improve the experience for others. Family's member of people affected by Learning disability will have opportunity to contribute to a tool that will aid the care of their loved one. The researcher had brother who is learning disability and she wants to help people like her brother to have a better life. The researcher hopes to be able to deliver alternative solution guidelines to help improve the quality of the care for family caregivers in winder community of learning disability's caregiver in Thailand.

B.11.   What are the theoretical frameworks or methodological approaches being used?

The researcher uses a qualitative approach to collect co-design methodology (E. N. Sanders & Stappers, 2008) to emphasising of the user needs comes from iteratively passing through stage of Discovery problems, Create/ ideation, and Deliver/implementation (Lewrick, Link, & Leifer, 20). Co-design approach using social construction on the participant.

First part of this research, the researcher will collect data using depth interview online over skype. A phase two of the research will focus on implementation of idea to design prototype/ or solution created from the outcomes from phase one. In this phase we will test and improve the design with participants, using a workshop to test the usability of the design outcome. A co-design workshop will be held in country to develop the design ideas, and help facilitate the sharing of information about usability of product (E. B. N. Sanders & Stappers, 2014). Co-design use a combination of design and research orientated methods to work with the participants, enabling the participants to contribute to the final outcome (E. N. Sanders & Stappers, 2008). The aim is to get feedback from caregivers who assist family member with learning disability to improve their quality of caring their loved one.

B.12.   How will data be gathered and processed?

Fin the first phase, data will be collected via online interviews, it will be administered with 5-7 family caregivers of adults, who may be mixture of parental and sibling relationships. The data will be gathered from an in-depth interview over skype with the caregiver with learning disabled. Participants selected with include a relative or caregiver with a LD person. Each session will last no longer than an hour. The researcher will record audio with Otter apps (iOS apps on iPhone for record and take meeting note) to record the conversation between participant and researcher.The Otter apps was chosen due to it easier to use mobile phone and it help the researcher conduct the interviewing naturally.

The consent form and participant information will be sent to the participants in advance of the interview. The researcher will use QuickTime software (software on Mac computer) to screen record the video and verify their consent. The participant will be received the pre-prepared session script that will be include the duration of the session and the action will be undertaken. Each session will have a special objective to gather user insight of caring adults with learning disability. An output will be developed from phase one as a mock-up prototype to be explored further in phase two.

Phase two of research will focus on usability test of design prototype (May be an app i.e. smartphone application). Co-creation process which work with family member or caregivers. This session will take around 30 min. The participant will be audio recorded while they be asked to talk their opinions while using the developed prototype. Then will have small discussion about their thoughts into the functions they would want to keep, change or remove. The researcher will take photos of the participants interactions in the workshop sections (it will only focus on hands and sheet, and will exclude any identifying information, such as their face).

Data will be gathered using audio recording and notes by the researcher. Material created by participant during the activity sessions will be photographed. The interview will be conducted in Thailand to find customer insights, then continue to analyse the data by using a transcript from the interview by using Vivo or similar software to find the key themes and narrative analysis.

B.13. How will the data be analysed?

Please provide the statistical (for quantitative research) or methodological (for qualitative or other research) justification for analysing the data in this way.

The research will be based on co-design methodologies (E. N. Sanders & Stappers, 2008) and qualitative methodologies (Crouch & Pearce, 2012).

The researcher will use design thinking methodologies to systematic analyse the data as outline below
1). Group and arrange different type of data by what/ who/ when/why and how.
2). Review and mapping the evidence and data to connect the pattern of data. This aim is to understand overall themes and concepts.
3) Prioritise data by plot graph separate data by four quarter, which include two axis of possibility (easy/hard), and expectations (surprise/expected)
4). Findings will be analysed and reported by the researcher using thematic analysis.

This research will use design techniques to create a final design prototype. The researcher going to do a form of narrative analysis around the key construct that can then be developed using design tools to develop the prototype. These include a persona to analyse demographic data about the participants. Used user insights from the interview will be used to create a general persona (there will be no identifying information to one participant) (Martin & Hanington, 2012). Potential other tools include a stakeholder map and a service design blueprint (Bitner, Ostrom, & Morgan, 2008) The solutions will be designed using a combination of design thinking theories and industrial product design skills. The service design methods and theories will be used together with industrial product design approaches to produce final results, such as the application for the disabled person and the guardian, touch-point products and support service (Stickdorn & Schneider, 2011).

B.14. Has any peer review taken place?   ☒ Yes ☐ No

If your answer is 'Yes', please specify and provide evidence e.g. a letter of confirmation.

☐ *AUT Competitive Grant*   ☐ *External Competitive Research Grant*
☒ *PGR1*   ☐ *PGR2*   ☐ *PGR9*   ☐ *Independent Peer Review**

Optional exemplars for evidencing peer review are available from the Ministry of Health (HDEC) website (http://ethics.health.govt.nz/) or from the Forms section of the Research Ethics website (http://aut.ac.nz/researchethics)

C.   *General Project Details*

C.1.   Likely Research Output

C.1.1.   What are the likely outputs of this research?

☐ *a thesis*   ☒ *a dissertation*   ☐ *a research paper*   ☐ *a journal article*
☐ *a book*   ☐ *conference paper*   ☐ *a documentary*   ☒ *an exhibition*
☐ *a film*   ☐ *some other artwork*   ☒ *other academic publications or presentations*
☒ *Some other output, please specify*

Prototype of printed graphic elements /and/or a prototype of smartphone application

F.3.   What consultation has occurred to ensure that this will be effective?

Please provide evidence of the consultation that has occurred.

Arunothai chaichuay Gernert (Co-founder of Arunothai's project, Educational Therapist)

G.   *Informed and Voluntary Consent*

G.1.   How will information about the project be given to potential participants?

A copy of all information that will be given to prospective participants is to be attached to this Application Form. If written information is to be provided to participants, you are advised to use the Information Sheet exemplar. The language in which the information is provided is to be appropriate to the potential participants and translations need to be provided when necessary.

Participants will be notified of the research through Arohai's newsletter, enabling potential participants to contact the researcher if they want to participate in the in-depth interviews and focus group.

G.2.   How will the consent of participants be obtained and evidenced?

AUTEC requires consent to be obtained and usually evidenced in writing. A copy of the Consent Form which will be used is to be attached to this application. If this will not be the case, please provide a justification for the alternative approach and details of the alternative consent process. Please note that consent must be obtained from any participant aged 16 years or older. Participants under 16 years of age are unable to give consent, which needs to be given by their parent or legal guardian. AUTEC requires that participants under the age of 16 assent to their participation. When the nature of the research requires it, AUTEC may also require that consent be sought from parents or legal guardians for participants aged between 16 and twenty years. For further information please refer to AUTEC's <u>Applying for Ethics Approval: Guidelines and Procedures.</u>

Participants will need to provide written consent to the study in focus group, which will also include consent to be photographed and filmed with audio in the online interview section. Photographs and video will not be shared outside the research team.

G.3.   Will any of the participants have difficulty giving informed consent on their own behalf?   ☐ Yes ☒ No

Please consider physical condition, cognitive status, age, language, legal status, or other barriers.

If the answer is 'Yes' please answer G.3.1 and the following sections, otherwise please answer G.4 and continue from there.

G.3.1.   If participants are not competent to give fully informed consent, who will consent on their behalf?

Researchers are advised that the circumstances in which consent is legally able to be given by a person on behalf of another are very constrained. Generally speaking, only parents or legal guardians may give consent on behalf of a legal minor and only a person with an enduring power of attorney may give consent on behalf of an adult who lacks capacity.

G.3.2.   How will these participants be asked to provide assent to participation?

Whenever consent by another person is possible and legally acceptable, it is still necessary to take the wishes of the participant into account, taking into consideration any limitations they may have in understanding or communicating them.

G.4.   Is there a need for translation or interpreting?   ☒ Yes ☐ No

If your answer is 'Yes', please provide copies of any translations with this application and any Confidentiality Agreement required for translators or interpreters.

Information sheet and consent form is written bilingually. The information has been written first in Thai and then translated to English.

H.   *Respect for Rights of Privacy and Confidentiality*

H.1.   How will the researchers respect the privacy and confidentiality of participants?

Please note that anonymity and confidentiality are different. For AUTEC's purposes, 'Anonymity' means that the researcher is unable to identify who the participant is in any given case. If the participants will be anonymous, please state how, otherwise, if the researcher will know who the participants are, please describe how the participants' privacy issues and the confidentiality of their information will be managed.

Participant will be given pseudonyms to protect their identity. . Participant will be asked to keep the identity private of other participants in the focus group.

H.2.   Will any participants be identifiable in the research outputs or findings?   ☒ Yes ☐ No

If your answer is 'Yes", please answer H.2.1, otherwise please answer H.3

H.2.1.   What level of confidentiality is able to be offered to participants and how will this be managed?

If the research involves small or distinctive groups of participants or procedures such as interviews conducted at the worksite, or focus groups with peers, researchers should identify the level of participant confidentiality that can be offered in the Information Sheet. If participants or groups will be identified, please state why this is appropriate, how this will happen, and how the participants will give consent.

The researcher will identify the level of participant confidentiality in the Information Sheet. Individual participants will be identified in the final report using a pseudonym of their choice. Any information that may identify them will either be removed or blocked.

H.3.   What information on the participants will be obtained from third parties?

This includes use of third parties, such as employers or professional organisations, in recruitment.

Arunothai's organisation will have contact details of some participants prior to the study taking place. The researcher will contact potential participant thought this organisation by email through a newsletter and some of participant might be selected by organiser.

H.4.   How will potential participants' contact details be obtained for the purposes of recruitment?

When potential participant see the advertisement, if they want to take part in the study. They will contact the researcher directly to view the contact detail. Once that participant confirmed, the participant will be contacted by the researcher both of interview and focus group with co-design workshop.

H.5.   What identifiable information on the participants will be given to third parties?

No identifiable info will be given to third parties.

H.6.   Who will have access to the data during the data collection and analysis stages?

The researcher

H.7.   Who will have access to the data after the findings have been produced?

The researcher and supervisors

H.8.   Are there any plans for the future use of the data beyond those already described?   ☐ Yes ☒ No

The applicant's attention is drawn to the requirements of the Privacy Act 1993 (see Appendix I of AUTEC's Applying for Ethics Approval: Guidelines and Procedures). Information may only be used for the purpose for which it was collected so if there are plans for the future use of the data, then this needs to be explained in the Information Sheets for participants. If you have answered 'Yes' to this question, please answer section H.8.1.1 and continue from there. If you answered 'No' to this question, please go to section H.9 and proceed from there.

H.8.1.1   If data will be stored in a database, who will have access to that information, how will it be used, for what will it be used, and how have participants consented to this?

H.8.1.2   Will any contact details be stored for future use and if so, who will have access to them, how will they be used, for what will they be used, and how have participants consented to this?

H.9.   Where will the data be stored once the analysis is complete?

Please provide the exact storage location. AUTEC normally requires that the data be stored securely on AUT premises in a location separate from the consent forms. Electronic data should be downloaded to an external storage device (e.g. an external hard drive, a memory stick etc.) and securely stored. If you are proposing an alternative arrangement, please explain why.

Data will be stored in Amabel Hunting's office at the AUT city campus. The digital data will be stored securely on external hard drive in Amabel Hunting's office.

H.9.1.   For how long will the data be stored after completion of analysis?

AUTEC normally requires that the data be stored securely for a minimum of six years, or ten years for health data. If you are proposing an alternative arrangement, please explain why.

For a minimum of six years.

H.9.2.   How will the data be destroyed?

If the data will not be destroyed, please explain why, identify how it will be safely maintained, and provide appropriate informed consent protocols.

The digital data will be deleted using erase thought disk utility on Mac. Hard copy will be shredded along with written consent form.

H.10. Who will have access to the Consent Forms?

The Researchers and primary supervisor.

H.11. Where will the completed Consent Forms be stored?

Please provide the exact storage location. AUTEC normally requires that the Consent Forms be stored securely on AUT premises in a location separate from the data. If you are proposing an alternative arrangement, please explain why.

The Consent Forms will be scan and destroy the originals. It will be stored in lockable cabinet locate in AUT art and design building (WE408, Amabel's office)that will be separate to the data.

H.11.1. For how long will the completed Consent Forms be stored?

AUTEC normally requires that the Consent Forms be stored securely for a minimum of six years, or ten years in the case of research involving health data. If you are proposing an alternative arrangement, please explain why.

Six years minimum.

H.11.2. How will the Consent Forms be destroyed?

If the Consent Forms will not be destroyed, please explain why.

The consent will be shredded.

H.12. Does your research involve the collection of personally identifiable and sensitive data?   ☐ Yes ☒ No

Sensitive data can be used to identify an individual, object or location and has a risk of discrimination, harm or unwanted attention. Sensitive data potentially poses a substantial threat to those who are or who have been involved in it, especially if it is shared inappropriately, or if it falls into the wrong hands. If you have answered 'Yes' please identify what data is being collected and how it is sensitive and provide a Data Safety Management Protocol (see the Forms section of the Research Ethics website for a guide to drafting one). If the answer is 'No', please answer H.13 and continue from there.

H.13. Does your project involve the use of previously collected information or biological samples for which there was no explicit consent for this research?   ☐ Yes ☒ No

If the answer is 'Yes' please answer H.13.1 and the following sections, otherwise please answer H.14 and continue from there.

H.13.1. What previously collected data will be involved?

H.13.2. Who collected the data originally?

H.13.2.1 Why was the information originally collected?

H.13.2.2 For what purposes was consent originally given when the information was collected?

H.13.3. How will the data be accessed?

H.14. Does your research involve the collection of information about organisational practices?   ☐ Yes ☒ No

AUTEC applies a broad definition to the term 'organisations'. It could include for example, businesses, hospitals or clinics, schools, or sports clubs and teams If the answer is 'Yes' please answer H.14.1, otherwise please answer I.1 and continue from there.

H.14.1. How will the authorisation to access the organisation or its staff for research purposes be obtained?

H.14.2. Could disclosure of this information potentially disadvantage the oganisation or the participants?   ☐ Yes ☒ No

If your answer is 'Yes", please answer H.14.2.1, otherwise please answer H.14.3

H.14.2.1 How will the risks associated with potential disadvantages be managed?

H.14.3. Will the particpants or anyone else in the oganisation be identified in this information? ☐ Yes ☒ No

If your answer is 'Yes", please answer H.14.3.1, otherwise please answer I.1 and continue from there.

H.14.3.1 How will the potential risks involved be managed?

If the research involves procedures such as interviews conducted at the worksite, or focus groups with peers, researchers should identify the level of participant confidentiality that can be offered in the Information Sheet.

I.   *Minimisation of risk*

I.1.   Risks to Participants

Please consider the possibility of moral, physical, psychological or emotional risks to participants, including issues of confidentiality and privacy, from the perspective of the participants, and not only from the perspective of someone familiar with the subject matter and research practices involved. Please clearly state what is likely to be an issue, how probable it is, and how this will be minimised or mitigated (e.g. participants do not need to answer a question that they find embarrassing, or they may terminate an interview, or there may be a qualified counsellor present in the interview, or the findings will be reported in a way that ensures that participants cannot be individually identified, etc.) Possible risks and their mitigation should be fully described in the Information Sheets for participants.

I.1.1. How much time will participants be required to give to the project?

1-2 hours in interview phase one, in phase two (testing usability) testing session lasting around 30 min

I.1.2. What level of discomfort or embarrassment may participants be likely to experience?

Low levels – the only discomfort could be caused by presenting ideas or they being asked to using App construction. In that case participants can choose not to patriciate.

I.1.3. In what ways might participants be at risk in this research?

Participant are not anticipated to experience such high risk or discomfort.

I.1.4. In what ways are the participants likely to experience risk or discomfort as a result of cultural, employment, financial or similar pressures?

Participant are not anticipated to experience such risk or discomfort. They may feel discomfort having been selected based on caregiving learning disability. The researcher will be empathetic and will support participant during co-design activity.

I.1.5. Will your project involve processes that are potentially disadvantageous to a person or group, such as the collection of information, images etc. which may expose that person/group to discrimination, criticism, or loss of privacy? ☐ Yes ☒ No

If your answer is 'Yes', please detail how these risks will be managed and how participants will be informed about them.

I.1.6. Will your research involve collection of information about illegal behaviour(s) which could place the participants at current or future risk of criminal or civil liability or be damaging to their financial standing, employability, professional or personal relationships? ☐ Yes ☒ No

If your answer is 'Yes', please detail how these risks will be managed and how participants will be informed about them.

I.1.7. If the participants are likely to experience any significant discomfort, embarrassment, incapacity, or psychological disturbance, please state what consideration you have given to the provision of counselling or post-interview support, at no cost to the participants, should it be required.

Adult research participants in Auckland are able to utilise counselling support from the AUT Counselling Team, otherwise you may have to consider local providers for participants who are located nationwide, or in some particular geographical area or who are children. You may discuss the potential for participant psychological impact or harm with the Head of AUT Counselling, if you require. Please check the relevant Frequently Asked Question on the research ethics website as well and ensure the appropriate wording in included in the Information Sheet when counselling opportunities need to be offered.

They're unlikely to need consoling.

I.1.8. Will any use of human remains, tissue or body fluids which does not require submission to a Health and Disability Ethics Committee occur in the research? ☐ Yes ☒ No

e.g. finger pricks, urine samples, etc. (please refer to section 13 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures). If your answer is yes, please provide full details of all arrangements, including details of agreements for

treatment, how participants will be able to request return of their samples in accordance with right 7 (9) of the Code of Health and Disability Services Consumers' Rights, etc.

I.1.9. Will this research involve potentially hazardous substances?	☐ Yes ☒ No

e.g. radioactive material, biological substances (please refer to section 15 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures *and the Hazardous Substances and New Organisms Act 1996).*

If the answer is 'Yes', please provide full details, including hazardous substance management plan.

I.2.   Risks to Researchers

If this project will involve interviewing participants in private dwellings, undertaking research in unfamiliar cultural contexts either in New Zealand or overseas, doing research in a place to which a travel warning applies, or going into similarly vulnerable situations, then a Researcher Safety protocol should be designed and appended to this application. This should identify simple and effective processes for keeping someone informed of the researcher's whereabouts and provide for appropriate levels of assistance. A guide to drafting one is provided in the forms section of the Research Ethics website*.*

I.2.1. Are the researchers likely to be at risk?	☒ Yes ☐ No

If the answer is 'Yes' please answer I.2.1.1 and then continue, otherwise please answer I.3 and continue from there.

I.2.1.1   In what ways might the researchers be at risk and how will this be managed?

I will travel overseas and visit participants in a public area at Arunothai's office. I will interview the participants on skype initially and the focus group will be held in the same city that my family live so I will send the contact details to my family. I will not be interviewing participants alone in their private space.

I.3.   Risks to AUT

I.3.1. Is AUT or its reputation likely to be at risk because of this research?	☐ Yes ☒ No

If the answer is 'Yes' please answer I.3.1.1 and then continue, otherwise please answer I.3.2 and continue from there.

I.3.1.1   In what ways might AUT be at risk in this research?

Please identify how and detail the processes that will be put in place to minimise any harm.

I.3.2. Are AUT staff and/or students likely to encounter physical hazards during this project?	☐ Yes ☒ No

If yes, please provide a hazard management protocol identifying how harm from these hazards will be eliminated or minimised.

J.   *Truthfulness and limitation of deception*

J.1.   How will feedback on or a summary of the research findings be disseminated to participants (individuals or groups)?

Please ensure that this information is included in the Information Sheet.

The researcher is planning to give them a report at the end that summarises 1-2 pages of the findings.

J.2. Does your research include any deception of the participants, such as non-disclosure of aims or use of control groups, concealment, or covert observations?	☐ Yes ☒ No

Deception of participants in research may involve deception, concealment or covert observation. Deception of participants conflicts with the principle of informed consent, but in some areas of research it may sometimes be justified to withhold information about the purposes and procedures of the research. Researchers must make clear the precise nature and extent of any deception and why it is thought necessary. Emphasis on the need for consent does not mean that covert research can never be approved. Any departure from the standard of properly informed consent must be acceptable when measured against possible benefit to the participants and the importance of the knowledge to be gained as a result of the project or teaching session. This must be addressed in all applications. Please refer to Section 2.4 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures when considering this question.

If the answer is 'Yes' please answer J.2.1 and the following sections, otherwise please answer J.3 and continue from there.

J.2.1.   Is deception involved?

J.2.2.   Why is this deception necessary?

J.2.3.   How will disclosure and informed consent be managed?

J.3.   Will this research involve use of a control group?   ☐ **Yes** ☒ **No**

If the answer is 'Yes' please answer J.3.1 and the following sections, otherwise please answer K.1 and continue from there.

J.3.1.   How will the Control Group be managed?

J.3.2.   What percentage of participants will be involved in the control group?

J.3.3.   What information about the use of a control group will be given to the participants and when?

K.   *Avoidance of Conflict of Interest*

Researchers have a responsibility to ensure that any conflict between their responsibilities as a researcher and other duties or responsibilities they have towards participants or others is adequately managed. For example, academic staff members who propose to involve their students as participants in research need to ensure that no conflict arises between their roles as teacher and researcher, particularly in view of the dependent relationship between student and teacher, and of the need to preserve integrity in assessment processes. Likewise researchers have a responsibility to ensure that any conflict of interest between participants is adequately managed for example, managers participating in the same research as their staff.

K.1.   What conflicts of interest are likely to arise as a consequence of the researchers' professional, social, financial, or cultural relationships?

There are no anticipated conflict of interest.

K.2.   What possibly coercive influences or power imbalances are there in the professional, social, financial, or cultural relationships between the researchers and the participants or between participants (e.g. dependent relationships such as teacher/student; parent/child; employer/employee; pastor/congregation etc.)?

I have had no previous direct involvement with Arunothai organisation despite my brother being in a similar situation. The organisation is only distributing information about the project to the participants and providing a meeting space for the focus group. They will not be taking part in any other way.

K.3.   How will these conflicts of interest, coercive influences or power imbalances be managed through the research's design and practice and how will any adverse effects that may arise from them be mitigated?

K.4.   Does your project involve payments or other financial inducements (including koha, reasonable contribution towards travel expenses or time, or entry into a modest prize draw) to participants?   ☒ **Yes** ☐ **No**

If the answer is 'Yes' please answer K.4.1 and the following sections, otherwise please answer K.5 and continue from there.

K.4.1.   What form will the payment, inducement, or koha take?

Coffee and tea break during activity

K.4.2.   Of what value will any payment, gift or koha be?

Approximately $25 in total.

K.4.3.   Will potential participants be informed about any payment, gift or koha as part of the recruitment process, and if so, why and how?

Participant will be aware of coffee break in the information presentation of the beginning of recruitment.

K.5.   Have any applications for financial support for this project been (or will be) made to a source external to AUT?   ☐ **Yes** ☒ **No**

If the answer is 'Yes' please answer K.5.1 and the following sections, otherwise please answer K.6 and continue from there.

❖   Late applications will be placed on the agenda for the following meeting.

❖   Late applications will be placed on the agenda for the following meeting.

Onwara Khongpaiboon   School of Art and Design 2020

MINIMAL RISK CHECKLIST

Your application may be eligible for delegated review if it poses no more than minimal risk of harm to participants. To assist AUTEC's Secretariat to screen the application for assignment to the correct review pathway, please complete the following checklist:

Does the research involve any of the following?

ANONYMOUS SURVEY ASSESSMENT

		Yes	No
1	The collection of anonymous and non-sensitive survey/questionnaire data only. *(If YES is checked, the application may receive an expedited review if the data is from adults and poses no foreseeable risks to participants OR where any foreseeable risk is no more than inconvenience – no further questions on this checklist need be answered.)*	☐	☒

MINIMAL RISK ASSESSMENT[1]

		Yes	No
2	Participants who are unable to give informed consent (including children under 16 years old), or who are particularly vulnerable or in a dependent situation, (e.g. people with learning difficulties, over-researched groups, people in care facilities, or patients highly dependent on medical care)?	☐	☒
3	A reasonable expectation of causing participants physical pain beyond mild discomfort, or that experienced by the participants on an every-day basis, or any emotional discomfort, embarrassment, or psychological or spiritual harm, (e.g. asking participants to recall upsetting events)?	☐	☒
4	Research processes which may elicit information about any participant's involvement in illegal activities, or activities that represent a risk to themselves or others, (e.g. drug use or professional misconduct)?	☐	☒
5	Collection of any human tissue, blood or other samples, or invasive or intrusive physical examination or testing?	☐	☒
6	The administration of any drugs, medicines, supplements, placebo or non-food substances?	☐	☒
7	An intervention of any form of exercise, or other physical regime that is different to the participants' normal activities (e.g. dietary, sleep)?	☐	☒
8	Participants who are being asked to give information of a personal nature about their colleagues, employers, teachers, or coaches (or any other person who is in a power relationship with them), and where the identity of participants or their organisation may be inferred?	☐	☒
9	Any situation which may put the researcher at risk of harm? (E.g. gathering data in private homes)?	☐	☒
10	The use of previously collected biological samples or identifiable personal information for which there was no explicit consent for this research?	☐	☒
11	Any matters of commercially sensitive information?	☐	☒
12	Any financial interest in the outcome of the research by any member(s) of the research team?	☐	☒
13	People who are not giving consent to be part of the study, or the use of any deception, concealment or covert observations in non-public places, including social media?	☐	☒
14	Participants who are in a dependent or unequal relationship with any member(s) of the research team (e.g. where the researcher is a lecturer/ teacher/ health care provider/ coach/ employer/ manager/ or relative etc.) of any of the participants?	☐	☒

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[1] If "No" is checked to all items 2-14, the application's status as Minimal Risk will be checked by the Secretariat, and may be forwarded to expedited review. Applications with more than Minimal Risk (any one "yes" to questions 2-14 above), and applications where the checklist is not completed will appear on AUTEC's next agenda.

Jpeg-of-ethic-Onara   *This version was last edited in March 2019*

APPENDIX 6 SERVICE DESIGN BLUEPRINT