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Autism toolkit: an online training program for laymen in rural India

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BOSTON UNIVERSITY
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**AUTISM TOOLKIT:
AN ONLINE TRAINING PROGRAM FOR LAYMEN IN RURAL INDIA**

by

ESTHER ZACHARIAH

B.O.T., Christian Medical College and Hospital – Vellore, 2015

Submitted in partial fulfillment of the
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Approved by

Academic Mentor

Karen Duddy, OTD, MHA, OTR/L
Lecturer of Occupational Therapy

Academic Advisor

Karen Jacobs, OT, Ed.D., OTR, CPE, FAOTA
Associate Dean for Digital Learning & Innovation
Clinical Professor of Occupational Therapy

“When a flower doesn’t bloom,
you fix the environment in which it grows,
not the flower.”

-Alexander Den Heijer

"We often hope that what we do is transformational,
but [more often] it's been transformative."

-Jubin Varghese

DEDICATION

I would like to dedicate this work to all those who are working in community mission hospital programs in India to serve those who fall through the cracks of a broken medical system.

I also would like to dedicate this to those who are constantly looking for innovative ideas to solve problems in India and around the world, especially during this pandemic.

ACKNOWLEDGMENTS

I would like to thank Dr. Karen Duddy, my academic mentor for invaluable feedback, support and encouragement throughout this program. This was not only limited to the doctoral project but to work and life as well. I also would like to acknowledge my family for all their support and prayers throughout this course. I cannot forget the immense strength my husband, Michael Peter, gave me. He has truly earned the title "Samwise Gamgee", a true companion and rock. Finally, I like to thank my God for orchestrating all my experiences that has finally culminated into this project and for the grace that has led me this far.

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AN ONLINE TRAINING PROGRAM FOR LAYMEN IN RURAL INDIA
ESTHER ZACHARIAH

Boston University, Sargent College of Health and Rehabilitation Sciences, 2020

Major Professor: Karen Duddy, OTD, MHA, OTR/L Lecturer of Occupational Therapy

ABSTRACT

The second-most populous country in the world, India, has many problems that need attention such as employment, providing health services in rural areas, access to education and many more (Worldometer, n.d.). Each issue that is present has multiple reasons for why they exist. The two problems addressed in this project are:

a) the increasing in the number of children diagnosed with Autism Spectrum Disorder (ASD) (Raina et al., 2017)

b) a high number of regular children/teenagers who drop out from school, 1 in every 10 to be precise (Gouda & Sekher, 2014).

Autism toolkit is an online training program for anyone, interested in helping children with ASD, who has completed their 8th grade. It aims to provide intervention to children in the Autism Spectrum Disorder in rural parts of India through training laypeople or non-specialized workers (NSWs). The training will be done using the principles of task-shifting as postulated by the World Health Organization. Task shifting involves equipping more hands to provide intervention (World Health Organization, 2008). There is evidence from studies, where task shifting was done in South Asia, suggesting the efficacy of such an approach in ASD-intervention (Divan et al., 2015).

Capacity building programs that help solve problems within each community are advantageous (DHHS, National Cancer Institute, 2005).

Research has also shown that interventions for autism delivered by a non-specialist provider produce benefits compared to no treatment at all or ‘treatment as usual’(Rahman et al., 2016). The program is designed to engage volunteering OTs across India and the world, who are comfortable to teach simple topics in Hindi, online.

PREFACE

"Occupational therapy (OT) is the art and science of enabling engagement in everyday living, through occupation; of enabling people to perform the occupations that foster health and wellbeing and of enabling a just and inclusive society, so that all people may participate to their potential in the daily occupations of life" (Dsouza, Galvaan, & Ramugonda, 2017) (p.105). It has been said that the different aspects of applying occupational therapy principles should be embraced within the various ecologies where it is practiced (Dsouza et al., 2017). Hence, in a country like India, it understood that the role of an occupational therapist needs to adapt to the situation one is in, which might be different from what is taught in standard textbooks that are written by western authors such as Willard and Spackman, Jane Case-Smith, Trombly, etc., to name a few.

The perspectives of these western authors are very different from the realities that are seen by an Occupational Therapist (OT) in India on diverse matters such as medical reimbursement, social policy, cultural barriers and many more. Applying their principles laid out in these standard OT books into regular practice, even in a premiere teaching OT department in India, the author herself, found it as a challenge. Hence, this project is directed to bridge this gap between the principle and practice of OT, and thereby design an adaptable resource for managing children with ASD, in India.

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GLOSSARY

Laymen: These are men and women who live in a rural community in India. They are considered as those who do not have the knowledge on the subject.

Non-specialized worker: These are laymen who have been given training to carry out a certain task.

Trainee: A person who is interested to learn. Considered as laymen in this project.

Trainer: A person who will be teaching a class. This is a volunteer occupational therapist in this program.

CHAPTER ONE – Introduction

The ‘*Autism toolkit*’ is a training program that consists of simplified intervention strategies for children in the Autism Spectrum Disorder (ASD). It will be taught to laymen recruited from within the same community in rural India. This project is about understanding the need for such a program and strategies for carrying out the same.

Devansh is a 4-year old child, who was recently diagnosed with ASD by a psychiatrist in the local community hospital, in a rural village of North India. His mother took him to the hospital when she found that he was not responding to his name and rocking himself throughout the day. She also noticed that he still didn't say his first words clearly; instead, he repeated dialogues from his favorite cartoon show. Her neighbors thought that he was possessed by an ‘evil spirit’ and wouldn't let their children play with him. She found a center that dealt with children with special needs and got him enrolled there. Devansh was scheduled to visit the center regularly to receive therapy there. The center had one occupational therapist and many other "community workers". He underwent treatment from the community workers guided by the occupational therapist (OT) who worked there.

One day, he had a meltdown as his shirt got wet, and the staff would not let him disrobe in the middle of a class. However, this escalated, and within seconds Devansh clasped the long braid of the staff member and wouldn't let go. She then screamed for help. When another staff member came in to ease the situation, he grabbed on to her hair as well. More staff came in to help out; after a few screams and many scratches, he finally let go of their hair. The team, traumatized by this, reported the incident. Devansh's

sessions were reduced to once a week until he settled, or until the staff learned how to handle such situations in a better manner.

There are many other stories, such as this one where the staff were not adequately trained to handle and provide intervention to children with ASD. There have been many instances where the center had tried to get more OTs to work with them. Even if they did, there was a high attrition rate as the setup was in a rural community with low pay. OTs preferred to move to higher-paying jobs to provide for their own families. Furthermore, many places don't even have OTs, to support therapy for children diagnosed with ASD.

There are also other cases across the country, where another child with ASD, whose name was Srikanth, was tied up in dark rooms in an attempt to protect him from running off outside, on to the main road and harm himself in an accident. This measure was used surely due to a lack of awareness and the unavailability of therapists in the community. There is another instance where a teenager with Autism had developed sexual issues, which soon became a social concern to the village and his family. The above are some of the many consequences of delayed early intervention in India for children with ASD.

The importance of early intervention is not understood by most parents and leaders (Desai, Divan, Wertz, & Patel, 2012). Some of a ASD parent's fundamental concerns are

1. how they are going to meet unfamiliar challenges in the upbringing of their child,
2. caring for the child's basic needs and

3. finding a way for their child to fit into the milieu of everyday life (Desai et al., 2012).

With the present (rough) estimate of children with ASD living in India being 1 in every 750 children (Raina et al., 2017) (Chauhan et al., 2019), there is a need for appropriate therapeutic services to be made available to them. Management of ASD in a large population with limited resources, in a country like India, would need many therapists, from different disciplines, to meet this need. In the meantime (before developing a dependable service of therapists), most of these children would suffer neglect (Divan et al., 2015), as described in the stories of Devansh and Srikanth.

In 2015, along with 193 countries, the United Nations (UN) proposed and launched the Sustainable Developmental Goals (SDGs) to focus on the various problems world-wide (UNDP, 2007). It describes 17 goals (UNDP, 2007) that mirror many issues faced by those in rural India (India, 2017). The Prime minister of India, Narendra Modi stated in his speech to the United Nations Sustainable Development Summit in September 2015 that, "Sustainable development of 1/6th of humanity will be of great consequence to the world and our beautiful planet." H. E Jan Eliasson, the Deputy Secretary-General to the United Nations, talked about a "horizontal thinking" approach. This approach was described at the World Government Summit in 2016 where he stressed to come up with solutions that simultaneously targeted more than one SDGs, as compared to one, as compared to working on one goal at a time (World Government Summit, n.d.). Innovative community-based solutions that simultaneously address two or more problems, would be more effective in a community. For this reason, the author has

developed an innovative solution that is designed to address several barriers that limit the provision of therapeutic services to families and children with Autism in rural India.

A horizontal thinking approach was used to address two problems, where there were many SDGs were addressed in one solution. The two problems that being considered together are:

- the lack of services to children with ASD who live in rural India and
- the scarcity of opportunities available to community members working in low-paying jobs in rural India.

The context: Rural India and existing community health programs

India has many non-governmental organizations (NGOs) that work towards the betterment of the community they serve. These NGOs work in various fields like agriculture, climate change, human trafficking, mother and child care, to name a few. These organizations are part of an existing network that include a teaching medical institution (CMC), a healthcare mission organization (EHA) and a local community project (ANUGRAH). These are briefly described below.

Christian Medical College (CMC) Vellore

This is a premiere teaching medical institution in South India that provides undergraduate and post graduate courses in medicine (all specialties) along with allied health service courses. It is located in the city of Vellore in the state of Tamil Nadu, India. It is maintained by the Christian Medical College Vellore Association, a registered society formed by over 50 different Indian Christian churches and Christian organizations which run around 225 hospitals, health centers and dispensaries throughout the country,

most located in remote rural areas. The aim is to train dedicated persons to provide healthcare in the spirit of Christ through these remote hospitals (Christian Medical College, 2020).

CMC encourages interested candidates to apply for admission to the college through the Minority Network (MN) category. The MN network comprises of mission hospitals which are connected to the CMC Association. This place the student in a better position to get a seat in the college courses. Once the student gains the admission as a ‘sponsored candidate’ he or she is required by an agreement to serve for a minimum of 2 years in a needy area as deputed by the Minority Network, following his/her course of training (Christian Medical College, 2020).

Emmanuel Hospital Association (EHA)

EHA is a network of Christian mission hospitals scattered mostly in North India, that is part of the Minority Network. It has 20 hospitals and 40 community-based projects across North, Northeast and central India (Emmanuel Hospital Association, n.d.). The EHA organizational history relays between 1950 and 1970 there was a large-scale exodus from India of medical pioneers who were mostly European missionaries. In a crisis of leadership, a federation of mission hospitals was formed. EHA is now the most significant Christian non-governmental provider of healthcare in India. Equipped with around 180 doctors and specialists they meet the medical needs of approximately 96,000 inpatients and 871,000 outpatients. Along with 950 nurses and seven other nursing schools, they also have trained around 400 non-professional workers to support the massive inflow of patients (Emmanuel Hospital Association, n.d.).

Anugrah Project

The Anugrah Project is one of the community projects that come under the umbrella of EHA. It is situated in Herbertpur, Uttarakhand, India. It is an NGO that has 15 staff who cater to the needs of almost 140 disabled children in the community of Herbertpur (M. Sam, personal communication, April 14, 2020). Out of these staff, there is currently only one OT, one PT and one special educator. The rest of the team are mostly non-professional workers. It is essential to add here that on an average, there are currently ten children with Autism who are catered to in this program (M. Sam, personal communication, April 14, 2020).

Conclusion

The above entities are collaborative organizations can work together to address the specific issues raised by the author. The author had attended college in CMC as a sponsored candidate by EHA. She was posted in Anugrah Project, a rural NGO, for her service obligation for two years. She has understood the existing system and its needs, first-hand. She hopes that the project will contribute to the efforts of many in these organizations and those who are served by them, especially to the children and their families who are living with ASD in these rural communities.

CHAPTER TWO – Theoretical and Evidence Base

Prevalence of children with Autism Spectrum Disorder in rural India

Autism Spectrum Disorders or ASD are now being increasingly recognized in developing countries like India. There are however, very few detailed studies about the prevalence of children with ASD. A systematic review done in 2019 reports that the pooled percentage of children with Autism in the rural setting is 0.11 [95% confidence interval (CI) 0.01-0.02] aged between 1–18 years and 0.09 [95% CI 0.02–0.16] for the children in the urban population aged between 0-15 years of age (Chauhan et al., 2019). Raina et al. (2017) stated that the prevalence of ASD cases ranges from 0.07% to 1.8%, these numbers were from various regions and countries. Raina et al. (2017), he stated that the prevalence of ASD was 0.15% [95% CI 0.15–0.25], after assessing 28, 070 children urban, rural and tribal areas in Himachal Pradesh, India. They also found that there has been an increase in the numbers may be due to greater awareness, broadening of ASD diagnostic criteria, lower age at diagnosis and diagnostic substitution (Raina et al., 2017). Chauhan et al. (2019) on the other hand, discuss about an "under-recognition" of ASD due to delays in diagnosing a case at a young age.

Acknowledging the work of Chauhan et al. (2019), it seems to be impossible to understand the exact estimate of children with ASD in India due to the unavailability of a widespread epidemiological studies. However, a rough estimate was established based on the pooled percentage from the work of Raina et al. (2017) i.e., 0.15% [95% CI 0.15-0.25] prevalence and Chauhan et al. (2019) i.e., 0.11% [95% CI 0.01-0.02] prevalence in the rural populations of India. This calculation was approximated to 1 per 750 children

who lived with ASD in rural India. This was done to understand the need for this project in rural India.

Effects of Living with Autism

For each child who lives with Autism, there is a family that is being affected along as well. These families, struggle to understand how to help their child (Minhas et al., 2015). The following are the key findings of a study conducted in India, which highlights the challenges of the families caring for ASD children (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012). The above findings also correspond with the author's personal experiences while working in these areas.

1. There is a tremendous strain on these families due to competing commitments, and cultural norms often lead to initial social withdrawal from their extended families and society.
2. The resulting impact is multidimensional, not only involving the personal sphere but also extending into the wider community, with negative experiences of discrimination.
3. Even parents in urban areas have sparse help from health care providers and informal social networks. (In rural areas the ignorance is abysmal, with no awareness or guidance.)
4. Professionals from the health, education, and charitable organization sectors have a low awareness of the unique needs of these patients and their families, living with ASD.

5. Finally, as a consequence of these experiences, there are several unmet needs, such as therapeutic guidance, to be able to take care of their autistic children, help from the government, etc., of these isolated families having limited access to multidisciplinary, evidence-based services for ASD (Divan et al., 2012).

As mentioned above, children with Autism Spectrum Disorder (ASD) generally require a combination of therapies and interventions to address their constellation of symptoms. Evidence-based interventions such as Applied Behavior Analysis (ABA), Sensory Integration (SI) Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH), Developmental or Integrative models (DIR) have been described in the management of Autism. These intervention approaches need an individualized and a family-centred approach by a highly specialized therapist, requiring a low child-to-therapist ratio (Myers et al., 2007). However, the existing awareness and care for disorders like Autism are very primitive and sparse in rural India, due to the paucity of trained therapists and appropriate infrastructure (Kalra, Seth, & Sapra, 2005; Minhas et al., 2015). For example, a child with Autism will need to have sessions that are administered on a one-on-one basis as compared to a group-based session where social-emotional skills are low. Due to the high demand for therapists in rural India to meet this need, individual sessions cannot be held. Furthermore, if the therapist were to go for house-visits, they might be able to cover not more than 10–12 families a week, due to time lost in travelling to their rural homes. The latter being far apart and difficult to access.

Looking into the aspect of low social acceptance of children with ASD in an

Indian context, parents face rejection from the community they live in due to strong belief in 'Karma' or the 'Will of God' (Minhas et al., 2015). The author has personally witnessed the death of a child due to neglect in care due to such notions. The parents believed that the child was suffering for his past life's sins; and so, it was better that he “passed on to the next life.” This neglect of the children, coupled with a scarcity of therapists to deliver the right intervention, has worsened the situation in the rural communities (Minhas et al., 2015). Alternatively, some religious leaders used the term "God's will" to interpret to the parents that it was their divine duty to take care of a child with a disability and hence they would be rewarded in the “afterlife.” Parents of these children often took great comfort and were more motivated to care for their unique child. (Minhas et al., 2015) However, these parents shared the need for professional guidance to do so.

To address the lack of trained therapists and awareness and care for disorders like Autism, there is a need for appropriate infrastructure and services, along with systematic dissemination of evidence based information (Kalra, Seth, & Sapra, 2005; Minhas et al., 2015). Accessibility to quality therapy for autism (which is available in the cities) also into the rural areas in India, is a dire necessity to tackle this problem (Divan et al., 2015; Goel et al., 2016; Minhas et al., 2015).

In 2008 the World Health Organization introduced the idea of 'task-shifting' with recommendation and guidelines. Specifically, ‘task-shifting’ focuses on the redistribution of tasks amongst a health force team (World Health Organization, 2008). In this method, specific tasks are moved from highly qualified health workers to those who have fewer

qualifications. The health workers are trained, yet over a shorter period and are more available in the community (World Health Organization, 2008). Providing opportunities and training for community members to deliver services to children with Autism and their families may be an effective way to address these two pervasive problems. These community members are referred to as laypersons or non-specialized workers.

Non-specialized workers (NSWs) are those individuals who have not had the opportunity to continue their education after the 8th grade. To better understand why students do not finish their education, a study focused on the school system in the rural areas in India. It revealed that children dropped out of school for various reasons, one of the most common reasons being, financial problems (Gouda & Sekher, 2014). In many instances, these children start to work early in life to support their families. However, without proper education, the only jobs available to these young workers are those, that pay less.

Furthermore, there are fewer job opportunities in rural areas. A total of 31.99 million individuals of India's rural population live in households where one or more workers commutes from rural to urban areas for work (Gouda & Sekher, 2014). Therefore, having an opportunity for a higher wage job closer to their community would be an ideal solution. A training program to train those interested in working with children with Autism was developed as part of this project to address the need for higher-wage job opportunities in rural areas.

Autism Toolkit

This project is designed to use the community resources, i.e., members of the

community itself to meet a need within the community. The goal of the project is to train the non-specialized worker to deliver intervention services to the families living with an autistic child in the communities in rural India. It is developed to create more opportunities for meaningful employment at the primary prevention level for the non-specialized worker.

The program activities are focused on training along the lines of the United Nations' Sustainable Developmental Goals (SDGs). The SDGs include a list of 17 goals that are targeted towards ending poverty, improving health and education, reducing inequality, promoting economic growth, among other things (UNDP, 2007). The specific SDGs that will be addressed with this project are:

- Goal 3: Good health and well-being: Ensuring healthy lives and promoting the well-being for all at all ages is essential to sustain development. The authors aims to reach the children with ASD with evidence-based intervention.
- Goal 4: Quality Education: Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all. The author plans to provide quality education to the laymen who have dropped out of school after 8th or 10th grade.
- Goal 8: Decent Work and economic growth: Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all. Those trainees who successfully finish the course will be open to better job opportunities in rural hospitals or community non-governmental organizations (NGO).

- Goal 9: Industry, innovation and infrastructure: Build resilient infrastructure, promote inclusive and sustainable industrialization and foster innovation. The program is designed to be entirely online, thereby increasing the accessibility of the course.
- Goal 11: Sustainable cities and communities: Make cities and human settlements inclusive, safe, resilient and sustainable. The program is designed to use the resources present within the community to solve a problem. (UNDP, 2007)

Theoretical Models

A theoretical model was used to conceptualize the problem and guide the development of the program; this includes the incorporation of the SDGs. The model and approach used to develop the education module and the training approaches are derived from the Social Cognitive model and David Kolb's Experiential learning theory, respectively. These are explained in the paragraphs that follow.

Social Cognitive Model (SCM)

The SCM asserts that if individuals have a sense of personal agency or self-efficacy, they can change behaviors even when faced with obstacles. Exercising control would lead to motivation to act or persist through challenges (DHHS, National Cancer Institute, 2005). This program aims to build the capacity of members of the community itself to solve problems for itself.

Often children with Autism seem like an enigma, where a layperson could get quite unsure of what to do (Minhas et al., 2015). For example, when children with Autism display disruptive emotional outbursts, it is difficult to know how to intervene.

Education would address various options to understand the possible cause of the meltdown and provide alternatives to help calm the child. The aim would be to improve self-efficacy and behavioral capability to be able to deliver interventions to the children with Autism and to train their parents to be able to care for their children. The facilitation of skill development and understanding the vast array of an autistic child's behavior would help build the non-specialized worker's confidence.

Community organizing, as part of the Social Cognitive model, is a process through which community groups are helped to identify common problems, mobilize resources, develop and implement strategies to reach collective goals (DHHS, National Cancer Institute, 2005). Organizing the community to be able to identify the issues within the community and facilitating an issue selection would help them to become critically conscious of the factors that contribute to social problems. This process would help motivate participation in the solution to the issues they have identified. Participation would be facilitated by providing training to those who are interested (DHHS, National Cancer Institute, 2005).

David Kolb's Experiential Learning Theory

This theory was first proposed by David Kolb in 1984, who stated that. "Learning is the process whereby knowledge is created through the transformation of experience." David Kolb's theory was heavily based on the works of Dewey, Lewin and Piaget (Hickcox, 1990).

Dewey had focused on the role of the experience in learning. Dewey established that roots of experiential learning strongly as a humanist concept and not a behavior

tradition. He found that adult learners tend to demand that relevance and application of ideas be demonstrated and tested against their own experience. For example, he found that students felt "cheated" in college because their career expectations have not been met, and employers felt that the graduates were very unprepared for the work demands. Hence, there must be unity between actual experience and education (Dewey, 1983).

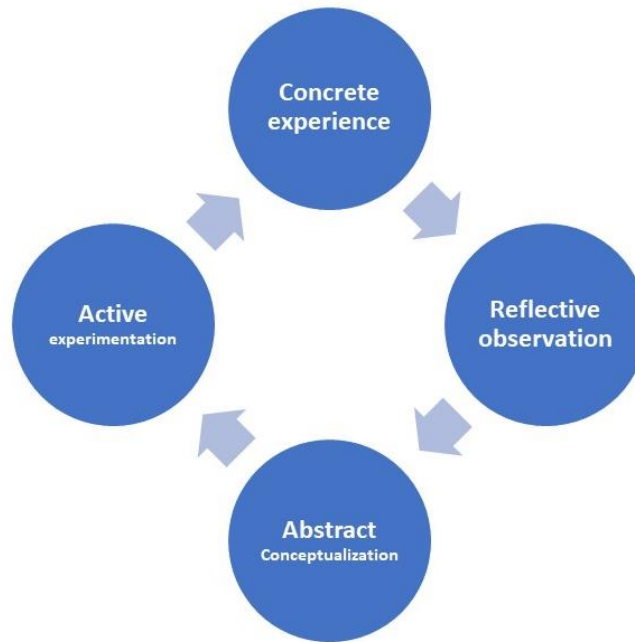
Lewin had looked into the importance of the learner being active in learning. Lewin's work had far-reaching practical significance; however, his main concern was to integrate social inquiry and social problem-solving. His experiments lead to the discovery that learning is best facilitated in an environment where there are dialectic tension and conflict between immediate, concrete experience and analytic detachment. His methods had a central focus to the value of personal experience in learning, which was completely different from the behaviorist themes of that time, which looked at knowledge acquisition as an impersonal, logical process that relied on detached, objective observation.

Piaget described intelligence as the result of the interaction of the person and the environment, i.e., his experience. His focus was on cognitive development processes- on the nature of intelligence and how it develops. This focus led to the development of experience-based educational curriculum that relied on the stages of cognitive development.

Kolb's experimental learning theory is a holistic perspective that combines experience, perception, cognition and behavior (Kolb, 2015). Kolb believes that learning is the process where knowledge is created through the transformation of experience (Kolb, n.d.).

Figure 2.1

The process of learning, as described by Kolb.



*Note: Adapted from Kolb, D. (2015). *Experiential learning: Experience as the source of learning and development* (2nd ed.). New Jersey: Person Education.*

In the second edition of his book, Kolb added his updates to the theory. These updates were based on the works of different contributors. The significance of these additions has provided the author on different methods that need to be used when teaching the laymen in rural India. They are the following:

1. Kolb stated that learning cycle is not a circle but a spiral. This concept means that a concept that we learn and understand today will be interpreted in a different, more transparent way at a later stage in life-based on our situational context. This was based on the work of Maturana and Varela (Chilean Biologists) (Kolb, 2015). Their work on ‘autopoiesis’

helped the author of the theory to draw parallels between the spiral of life and spiral of learning. He states that the spiral of learning that embeds us in a co-evolution of mutually transforming transactions between ourselves and the world around us (Kolb, 2015).

2. Kolb explained that the learning process is the foundation of neuronal structure. Thus, every learner is unique and interprets experiences differently. This was based on the work of James Zull (professor of Biology and Biochemistry) (Kolb, 2015). His work helped the author examine a link between learning theory and the brain. James' basic idea was that when there is learning from experience, neo-cortex is formed. In other words, he described education as the art of changing the brain (Kolb, 2015).
3. Pepper (American Philosopher) – Pepper's world hypotheses helped inform the author as he examined the implications to disciplinary learning spaces (Kolb, 2015). He mentions that the experiential theory is eclectic. He suggests that although he did not start to be eclectic, he was criticized for it. He, however, decided to persist in his multidisciplinary view to be able to further many professions and not just one with the principles of experiential learning theory. He chose to engender diversity (Kolb, 2015).

Core Assumptions. Assumptions about the experience are:

1. The unpredictability of experience can facilitate a holistic learning experience, where there are success and failure.

Assumptions about the students are:

2. Students are influenced by their experiences.
3. Students are capable of asking questions and self-reflect.
4. Students are inherently motivated to engage holistically (intellectually, emotionally, socially, etc.) in their learning process.
5. Students can have personal choices or preferences that drive their motivation.
6. Students want their values to be challenged.

Assumptions about the teachers or instructors are:

7. The teachers are open to learning new strategies and methods to teach.
8. Teachers are capable of knowing how to choose experiences to promote learning in their students carefully.
9. Instructors can recognize their own biases before being able to regulate the bias in their students.

How does learning happen? Learning is expected to occur in a spiral pattern through time and exposure (Kolb, 2015). Firstly, learners would need to start by experiencing and doing. For example, a student would be required to make a specific orthosis for a particular patient. Secondly, they would need to reflect on what happened during the experiment. In the example, they would reflect on what happened either by writing down a paragraph or discussing it with peers. Thirdly, they would need to analyze what is essential based on their own reflections. At this stage, they become actively critical in constructing knowledge (Lee, Flavell, Parsons, Parsons, & Falkmer, 2016). Fourthly, the student would have to generalize the learned knowledge into a "real world" situation.

Finally, they would have to apply their learned skills to a similar or different situation (Joshi, 2015).

Translation of the theories' Western values and beliefs. The foundational authors of this theory were mostly Western. However, it is vital that this program be designed with sensitivity to the cultural context and belief systems while applying the theoretical principles which originated from western authors. Some assumptions, made in Kolb's theory, are discussed below in light of its transferability to the Global South.

Firstly, the assumption that students are influenced by their experiences needs to be stated with a greater clarity. The student here cannot be seen as an independent individual. A salient challenge that is faced in the Global South is the cultural attitude to independence; this refers to the fact that the individual lives in inter-dependence with his/her family (Dsouza et al., 2017). According to Patall, Cooper, & Robinson (2008), intrinsic motivation was enhanced most for Asian Americans when trusted authority figures or peers made choices for them.

Secondly, the assumption that students want their values to be challenged might not wholly be the case in eastern countries. This assumption could be because of their educational background, strong religious beliefs and faith in alternative medicine (Dsouza et al., 2017).

Finally, the assumption that teachers want to change the way they teach. This may happen when the eastern students are reluctant to exercise their autonomy and become involved in their learning due to internal factors such as their attitude and lack of insight (Dsouza et al., 2017). The teachers would hence fall back to their older model of teaching

to support students.

Application of Kolb's theory

To determine how this theory was applied to the development of a learning module, a literature search was conducted. MeSH terms “experiential learning” and “disabilities” were used, limiting the search to the past five years and English publications only. The initial search yielded 42,679 articles. Next, the search was narrowed by including the term "occupational therapy"; this reduced the list to 8706 articles. It was further narrowed to only those articles that were conducted in Asia. It showed three articles, which specifically discussed the application of this theory in a similar cultural setting, namely the Global South, which was thought to be most applicable to this project.

Joshi, 2015 – Experiential learning with students in 9th grade in India

A study was done in India with students from the 9th standard. Joshi (2015) had designed a program based on Kolb's experiential learning model and studied its effectiveness. There were 2 phases to this study. Phase 1 consisted construction and standardization of the achievement test based on 8th standard curriculum. Phase 2 was the development and assessment of the effectiveness of Kolb's experiential learning model program. The socio-economic scale was used to assess high and low socio-economic status. The intelligence levels of the children were also evaluated.

In this study, the author developed an achievement test and studied her experiment and control groups after equating achievement levels and socio-economic status of the children of both groups before using the program. She found that the

program was effective. Students found that the program helped improve their achievement scores and problem-solving skills (Joshi, 2015).

Lim, 2018 – Experiential learning with occupational therapy students in Singapore

A study by Lim et al. (2018) sought to challenge students on their preconceived ideas on disabilities and reflect on the co-existence of the two communities. The paper was able to translate an experiential learning project from a Canadian context to a Singaporean context (Lim, Leet Tan, Lim, & Goh, 2018). The project brought persons with physical disabilities into the classroom of occupational therapy students to teach on the topic of professionalism and communication for two hours. There were also three consecutive meetings with the speakers. Students were taken through a reflective process using guided questions after each meeting. Students were also required to use the speaker and a case study and apply OT theories considering the person, environment and occupations. This was presented to the peers for feedback. The Multidimensional Attitudes Scales Towards Persons with a disability was used before the exercise and after.

The results showed that there was a successful improvement in attitudes towards disabilities (Lim et al., 2018). There was a holistic development of an appreciation for life and increased confidence in dealing with persons with disabilities as future OTs (Lim et al., 2018). The authors state the reflective exercises provided a mechanism for assimilating these experiences into OT practice (Lim et al., 2018).

Rahman, 2016- Parent-mediated intervention for children with ASD in South Asia in India and Pakistan (PASS)

Rahman et al. (2016) studied is the effectiveness of an intervention program

called the parent-mediated intervention for children with ASD in South Asia in India and Pakistan (PASS). The study by Rahman et al., (2016) explained the need for the paper as one that was required due to the shortage of evidence of the effectiveness of adapted interventions for low-income based countries. This paper is complicated as they tackle two separate aspects of the problems. The first being the training of the non-specialized worker and the second, the intervention.

The PASS program is an adapted version of the Preschool Autism Communication Trial (PACT). PACT was implemented and studied in the UK. The program aimed to reduce the social and communication impairments in children with Autism, using their parents as agents of change. They recognized the parents of children with Autism as an available resource. The program authors hypothesized that if the therapists taught parents to alter their communication environment with their child, then the impairments would reduce.

PASS took up this program and adapted it to the South Asian context, i.e., India and Pakistan. They also included a component of task-shifting where a non-specialized worker was trained to train parents. The study was able to effectively train non-specialized workers and transfer the learning to the parents to see results in the children with results. The authors of the study identified that the success of the key elements was the establishment of a clear supervisory cascade and development and maintenance of competencies of the staff involved. The intervention aimed to address only the child's communication difficulties and not the comorbid difficulties that come with Autism.

After the authors were able to identify an intervention program applicable to their

context, the authors were able to moderating or contextual factors in India and Pakistan. They were able to systematically tackle each of the moderators as they adapted the intervention program (PACT to PASS) . For example, the gender of the non-specialized worker was determined as the intervention plan progressed, through qualitative responses. According to Gauri et.al., (2015) only one parent asked for a female worker as it was culturally easier for them to have access to mothers at home. Another example of this was when deciding the education level of the non-specialized worker. Gauri et. al., (2015) mentions that even though experts advised a higher educational qualification, parents who were being trained mentioned that they valued the information the trainer gave them for their child, more than his/her educational qualification.

The above articles show that the principles of Kolb's theory need to be adapted to the context in which it is applied. Proper application of the principles has shown good results in being able to train to build confidence in providing intervention to children with Autism. The principles are also applicable to those in India at the 9th grade, which is similar to the program's target population. It shows great promise in being able to facilitate learning among the lay people in rural India.

Adaptation and effect of culture on the program

Similar to how Kolb was able to use the Experiential Learning Theory to describe the congruence of a person to his/her job-requirements, Yamazaki & Kayes (2004) mention that they found cross-culture learning methods can be used as learning opportunities. They state that a transactional approach to cross-cultural learning will promote learning as the person adapts to various cultures. They studied two cultures, the

"home-culture" and the "host-culture" and how the person interacts with them.

In the light of the above research, learners in the 'Autism Toolkit' program could be put in the same learning space to adapt western intervention programs for autistic children to their particular context i.e., rural India. The teaching methods are used as a way to teach learners to adapt intervention themselves rather than giving them "adapted information". This way, a universal program grounded on available interventions for children with Autism can be used, that is constantly adaptable to the place where it is being taught. Hence, each group of learners will have a guided semi-structured instruction manual, as an end product, for use after the course to implement the program. The application of the theories and evidences will be discussed in the Chapter 3.

CHAPTER THREE – Description of the Program

The Autism toolkit is an addendum to the efforts that are being done by many non-governmental organizations and community hospitals to reach out to the community they serve. The two aims of this project are, to deliver services for children who live in rural India with Autism Spectrum Disorder (ASD) and to provide opportunities to community members, working in low-paying (or no) jobs in rural India, through training with a probable chance for better incomes.

A rough estimate of prevalence of children with ASD living in India is 1 in every 750 children (Raina et al., 2017) (Chauhan et al., 2019), there is a need for appropriate therapeutic services, which need to reach them. Management of Autism in a large population, with limited resources, in a country like India, would require a vast number of highly trained therapists, to meet this need. The various disciplines would include occupational therapy (OT), physiotherapy (PT), speech therapy (ST) and others. Most of these children having no access at present to these evidence-based interventions, suffer neglect.

World Health Organization (WHO), in 2008, introduced the idea of 'task-shifting' with recommendation and guidelines. Specifically, this aims in the redistribution of tasks amongst a health force team. In this method, specific tasks are moved from highly qualified health workers to those who have fewer qualifications. They are trained, yet over a shorter period and are more available in the community (World Health Organization, 2008).

Through 'task-shifting,' a non-specialized worker (the trainee) will be provided

with an opportunity to continue their education after the 8th or the 10th grade. This method is essential as Gouda & Sekher (2014) et al., found out that 1 in every ten children/teenagers were dropping out of school due to various reasons. One of the main contributors to this was unaffordability due to a lower financial status. Later, as these children become young adults, they were not able to secure better-paying jobs due to a lack of education (Gouda & Sekher, 2014). It is assumed that providing an opportunity for this group of people would improve their chances of meaningful employment.

The use of the community resources, i.e., the laymen, to meet a need within the community was laid out by the National Cancer Institute (2005). It stated that building the capacity of a community to solve their problem makes them a more sustainable entity (DHHS, National Cancer Institute, 2005). The training of the non-specialized worker (the laymen) to deliver intervention services to the families living with an autistic child in the rural communities in India, would work to solve two problems. Furthermore, the training program also increases the chances of meaningful employment at the level of primary prevention for the non-specialized worker.

Key Elements of the Project

This project aims to reach out to the children in rural India living with ASD. The services provided primarily include Sensory Integration techniques, fine-motor skills training, sensory-related behavior management, etc. The program's costs are designed to be minimal, considering the population that it serves—using the resources that are widely available. Hence the process of designing this project needed creativity and practicality.

Throughout this chapter trainee, non-specialized worker or laymen have been

used interchangeably. Some of the critical elements of this project's successful implementation are as follows:

1. Recruiting volunteer occupational therapists (OTs) as trainers.

The OTs should possess at least a bachelor's degree in Occupational Therapy. Recruitment is based on their ability to teach in the local language. Using proper dissemination methods, the involvement of volunteer OTs to teach specific topics will be necessary for this project.

2. The program would be taught in Hindi.

The local language for the target community, for this project, is Hindi.

3. Classes would be provided on an online platform.

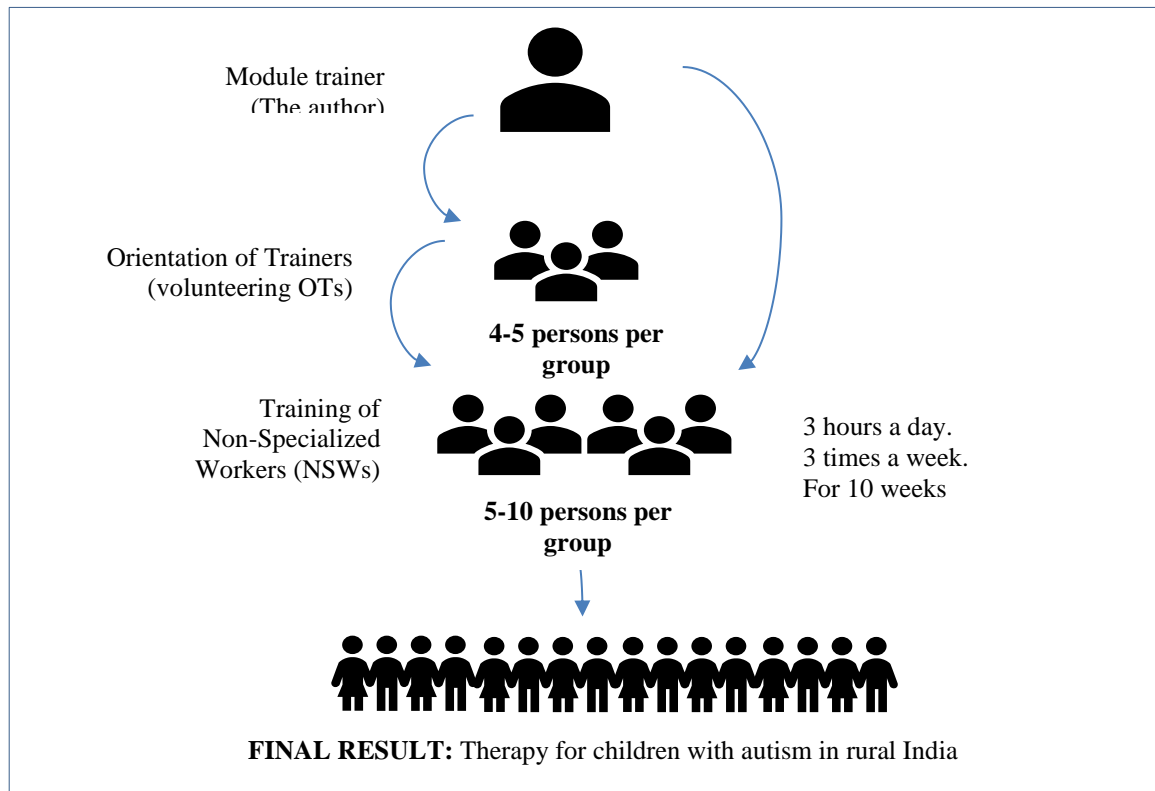
This will be organized alongside a hosting site.

4. The laymen (trainees) can gather at a common place where there is internet connection.

This will be organized alongside a hosting site.

5. Training can be done in the same city or community.

This will make it convenient for both the trainer (volunteer OTs) and the trainee (laymen).

Illustration 3.1*Schematic of the program*

The illustration above is an overview of the persons who will be involved in the training. The author will be required in the initial orientation of the volunteer OTs. These OTs will then be scheduled to train the Non-specialized workers (NSWs) or the trainees. These trainees will then be able to provide intervention, under the supervision of an OT, to the children living with ASD in rural India.

Trainers

The trainers would mostly be adequately qualified OTs from India or around the world. They should also be the OTs who either be already part of the community program OTs or have some experience working with children with ASD and their families.

Volunteers can have any amount of experience with children with ASD; hence new graduates may also be recruited based on the training they received.

Initially, trainers will be identified and be provided with an orientation to the program and the online teaching technology. Due to the level of the trainees, the topics have been kept simple. The trainees will be designated certain topics with reference points to prepare for a class. A single course may have 2-3 trainees at the maximum; this is so that the trainees can build a relationship and a comfort level with their trainers (Bastable, Gramet, Jacobs, & Sopczyk, 2011). Additional trainer inclusion/exclusion criteria include:

1. Need to have a degree in OT
2. Need to know Hindi fluently.
3. Need to be comfortable to teach using online technology
4. Need to be a voluntary instructor

Learning and teaching

This program has heavily based the program methodology on the work of David Kolb. In his revised book that was published in 2015, he mentions how learning needs to be carefully facilitated to make it meaningful for the learner (Kolb, 2015). He formulated that a person, after a 'concrete experience', makes observations and reflects on it. After that, he/she forms 'abstract concepts' and 'generalizations' that are based on the initial experience. Finally, he tries to test these 'abstract concepts' in new situations (Kolb, 2015).

Figure 3.1

Kolb's representation of learning and the role a trainer has to play



Note: Adapted from Kolb, D. (2015). *Experiential learning: Experience as the source of learning and development* (2nd ed.). New Jersey: Person Education.

In the figure above, Kolb's steps to learning have been considered. The process of learning takes the learner through the process of 'concrete experience', reflection, a chance to form abstract concepts and applying them in new situations. This figure also looks into the role a trainer has to play to facilitate learning (Kolb, 2015).

Kolb et al. (2015) make it clear that each person has a different way of grasping and understanding information. The learning styles of the learner are assessed to understand what the modalities that would need to be predominantly used (Kolb, 2015). This method was also used by Divan (2015) during their implementation of a similar program in rural India. She and her team targeted the parents of children with ASD and

provided regular training program to support them in taking care of the child with ASD. She recommended meeting the parent at their level of understanding for a better outcome (Divan et al., 2015).

Bastable et al. (2011) laid out a few essential teaching strategies for clients with low literacy. Some training methods, as explained by Bastable et al., that are included in this program, are as follows:

1. Build a trusting relationship
2. Made vivid and explicit as possible.
3. Could be taught one step at a time
4. Multiple teaching methods could be used that need fewer literacy skills.
5. Restating information in different ways could be done as an exercise during the training.
6. Keep motivation high.
7. Use repetition to reinforce information.
8. Principles of tailoring and cueing could be used as well. (Bastable et al., 2011)

The strategies mentioned above will inform better teaching methods such as using visual and verbal teaching methods based on styles of the students. A concrete experience, which would serve as kinesthetic learning would be given, i.e., a possible situation where a child with Autism is brought into the classroom as they try to listen to the instructor. A focus group discussion would be held similar to the method done by Lim et al., 2018 and Lee et al., 2016 in their studies; where the instructor would facilitate the group. During this discussion, they would get peer feedback. These sessions would have

guiding questions to facilitate reflection. The student's reflection patterns could also help to inform where more experiences would be required for the learning group. The use of this reduces traditional paper and pencil methods of assessment. It eases the trainee to use their local language to contribute to a discussion.

The calculation of a reflective score was implemented and quantified by Lee et al., 2016. Lim et al., 2018, thematically analyzed focus group discussions to comment on the learner's reflective changes. Kolb's theory uses an adaptive competency circle to assess outcomes or match the congruence of a person to the job requirements (Kolb, 2015). The author decided to use teach-back sessions at the end of the course to assess their proficiency in problem solving, adaptability of learnt topics and cultural sensitivity.

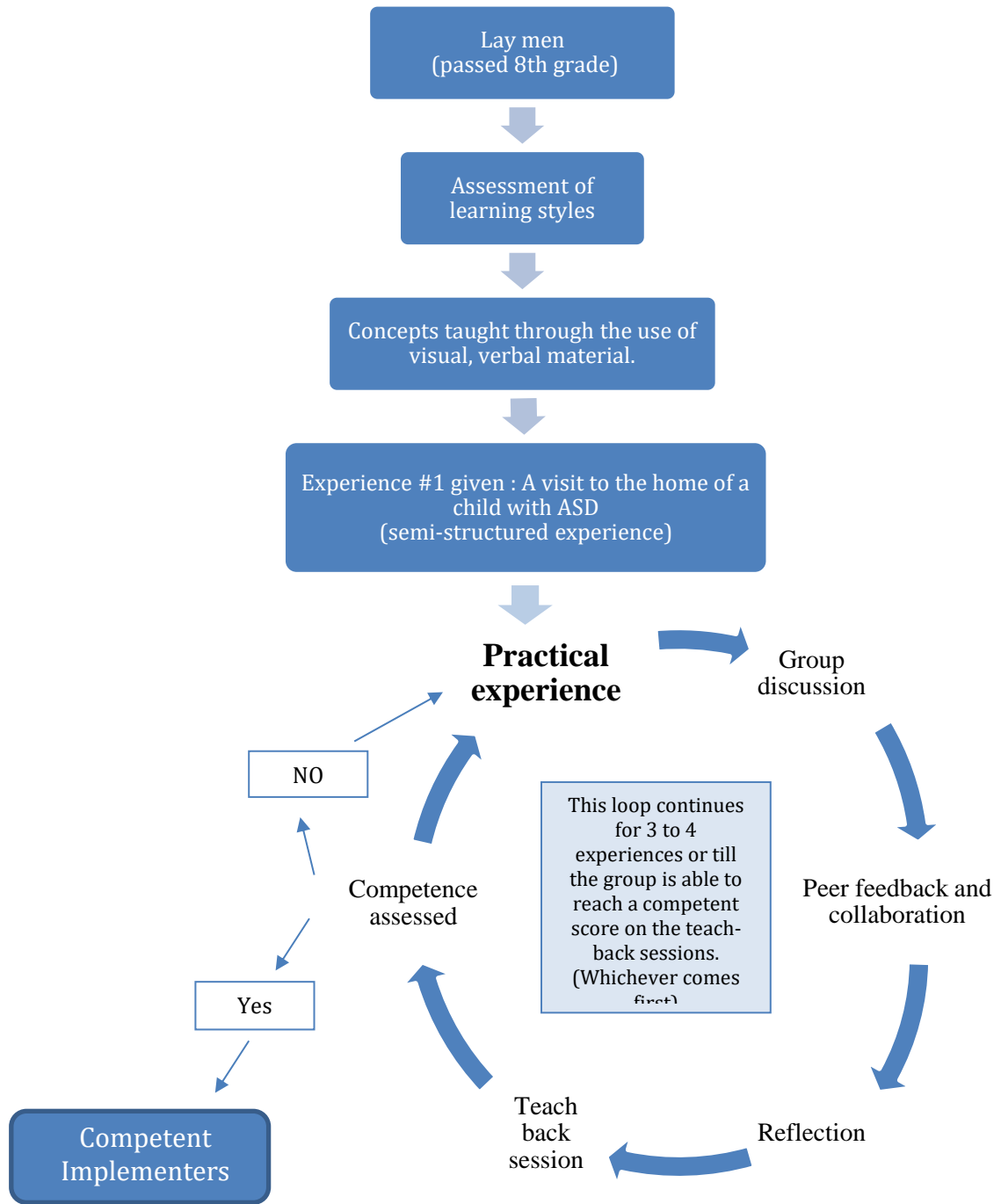
Application of Experiential Learning Theory and Other Essential Methods to Facilitate Learning

The number of trainers per course cycle has been limited to 2–3 trainers so that the trainees are able to build a relationship and comfort level with their trainers. The illustrations included in the program have been made culturally sensitive and simple. Considering that the trainee has completed their 8th or 10th grade, English will be used on PowerPoint slides sparingly (Bastable et al., 2011).

Using the above-mentioned strategies, a possible mechanism of change for this project is has been developed. This method is based on the research done by occupational therapy departments on two different contexts, Lim, Leet Tan, Lim, & Goh (2018) and Lee, Flavell, Parsons, Parsons, & Falkmer (2016). It is also using Experiential learning theory principles and the strategies as laid out by Bastable et.al., (2011).

Illustration 3.2

Learning flowchart



Note: A flowchart explains the series of events of a single learning course. It needs to be understood that "competent implementors" will then be evaluated using teach-back sessions to their peers.

This flowchart looks in to the skeletal framework of the program. This will be spread out across 10 weeks. The concrete experiences will be distributed throughout the program. The experiences will need to be designed based the learning styles of the class and the culture of the community where the training is being done. This process will be decided by the author on a case to case basis.

The customizable manual

The trainees will be given a module that will support their intervention programs with the community they serve. The program needs to take in account that values and cultural mindsets will vary in different communities (Kalra et al., 2005), the manual will be designed to recognize these cultural differences within each community.

The author has designed a universal program, grounded on available interventions for children with Autism, that is continuously adaptable to the place where it is being taught. Yamazaki & Kayes (2004) mentioned that they found cross-culture learning, can be used as learning opportunities. They state that a transactional approach to cross-cultural learning will lead the person to learn as they adapt to various cultures. Trainees in this program could be put in the same learning space to adapt western intervention programs for children with ASD to their particular context, i.e., rural India. This situation can hence be used a way to teach learners of this program to adapt intervention themselves rather than giving them "adapted information". Trainees will have a guided semi-structured instruction manual, as an end product, from the course.

Sessions

There will be 7–10 persons per group that would be considered at a time, as shown in the figure above. Each session would last for 3 hours a day. Topics have been kept simple; repetition will be used to reinforce important points (Bastable et al., 2011). The program will be done for three days a week and will last for ten weeks.

The live class session will allow for discussions and a chance to answer questions. The trainers will need to keep in mind the culture of the participants to be able to tailor the lessons to the group. For example, the group might not understand what a graph is. The trainer will need to use appropriate illustrations such as a water tank being filled up or a lift going up/down to a particular floor. If the group is not familiar with the concept of a lift, the example will need to be modified.

Some other considerations would be that the manual will need to be translated into the local language (Hindi) (Bastable et al., 2011). The focus group discussions could be based on the concrete experiences or abstract case scenarios.

Table 3.1*Session Break up*

Program Content	Topics to be covered	Theoretical Grounding	Evidence Base
WEEK 1: Introduction	<p>1. Introductions (done with an icebreaker activity)</p> <p>2. Learning styles: To understand the learning styles of the students in each group.^v</p> <p>3. Understanding the group's readiness to learn using the PEEK tool. ^v P- Physical readiness E- Emotional readiness E- Experiential readiness K- Knowledge readiness</p>	<p>Proper assessments can ensure adequate learning.</p> <p>Assessments prevent needless repetition of the known material, saves time and energy on the part of both the learner and the educator and helps to build rapport between the two parties.</p>	<p>Kitchie, S. (2011). Determinants of learning. In Bastable, S. B., Gramet, P., Jacobs, K. & Sopczyk, D. L.(2011.), <i>Health Professional as educator</i> (103-150). Boston: Jones and Bartlett Learning.</p>
WEEK 2: Introduction to Autism	<p>1. What is Autism?</p> <p>2. Why is it a problem?</p> <p>3. Cultural assessment</p> <p>4. Understanding the concept of</p> <p style="text-align: center;">Input ↓ Processing (this is where the problem lies in children with Autism) ↓ Output</p> <p>5. What are the signs and symptoms according to DSM-5</p> <p>6. Learn about Winne Dunn's model of sensory processing</p>	<p>A brief e-survey showed that the current level of understanding of Autism was shallow.</p> <p>A good understanding of the condition would help</p> <ul style="list-style-type: none"> - Remove any pre-existing cultural misconceptions in the learner's mind - It would help them to understand the reason behind interventions that would be discussed in the coming weeks. <p>Health educators who are knowledgeable about the culture and competent in the cultural assessment will be more successful at designing and implementing culturally relevant teaching programs.</p>	<p>Bastable, S. B. (2011). Gender, socioeconomic and cultural attributes of the learner. In Bastable, S. B., Gramet, P., Jacobs, K. & Sopczyk, D. L.(1st Ed.), <i>Health Professional as educator</i> (279-329). Boston: Jones and Bartlett Learning</p> <p>American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC: Author (pp. 50-51)</p>

<p>WEEK 3: Impact of disability on family members</p>	<ol style="list-style-type: none"> 1. Understanding the currently existing policies that are available in the Indian government system for the disabled. 2. Understanding the policies that are specific for children with Autism. 3. Discuss the stressors of a parent of a child with Autism that they have seen or heard. Discuss what research says about the issues that parents face in caring for children with disability. (financial and emotional) 4. Discuss the effects of having a sibling with a disability. (considering the sibling to be the future caregiver for the child with ASD) 	<p>Research talks about increases stress levels in parents of children with ASD compared to parents of children with other disabilities.</p> <p>It is crucial for coping and resiliency that all family members are included in the therapy of the child. This will benefit the whole family.</p>	<p>Miller-Kuhaneck, H. (2015). Autism spectrum disorder. In Case-Smith, J. & O'Brien, J. C. (7th Eds.), <i>Occupational therapy for children and adolescents</i> (pp 766- 793). Missouri: Elsevier</p>
<p>WEEK 4 & 5: Evaluation and screening for Autism</p>	<ol style="list-style-type: none"> 1. Discuss the behaviors that are more likely to be seen in children with ASD. 2. Learn about the screening tool M-Chat. 3. Use the M-Chat tool. (Simulation.) 4. Learn how to ask parents questions using the Sensory Profile 7. Use the Sensory Profile (simulation) 8. Learn about the ALARM guidelines. 6. Documentation. 	<p>The assessment tools such as the M-Chat and the Sensory profile provide a varied list of behaviors that help understand the actions that are seen in children with ASD.</p> <p>This would give the learners an idea of what to look for when screening for Autism. It would also help them to explain the same to the parents of the children with ASD.</p>	<p>Miller-Kuhaneck, H. (2015). Autism spectrum disorder. In Case-Smith, J. & O'Brien, J. C. (7th Eds.), <i>Occupational therapy for children and adolescents</i> (pp 766- 793). Missouri: Elsevier</p> <p>(Specific portions are taken from box 27-3 and Box 27-4)</p> <p>ALARM guidelines were retrieved from: http://www.theautismdoctor.com/the-a-l-a-r-m-surveillance-and-screening-algorithm-for-autism/</p>

WEEK 6, 7, 8: Intervention	<ol style="list-style-type: none"> 1. Interventions for engagement and interaction 2. Interventions to improve behavior and task completion 3. Interventions to improve comfort to reduce anxiety and fear 4. Interventions to develop motor skills and praxis 5. Interventions to improve play and ideational praxis <p>Special emphasis on:</p> <ol style="list-style-type: none"> 6. Task analysis 7. Therapeutic use of self 8. Reinforcement 9. Sensory diet administration 10. Alert Program engine concept 	<p>The interventions that would be taught using different methods such as:</p> <ol style="list-style-type: none"> 1. Lecture 2. Group discussion 3. One-to-one instruction (wherever possible) 4. Demonstration 5. Return demonstration 6. Gaming 7. Simulation (If resources are available) 8. Role-playing 9. Self-instruction (wherever applicable) <p>Learners should be challenged with a variety of learning experiences, and teachers should be worried about matching their instruction with the content they are teaching.</p>	<p>Miller-Kuhaneck, H. (2015). Autism spectrum disorder. In Case-Smith, J. & O'Brien, J. C. (7th Eds.), <i>Occupational therapy for children and adolescents</i> (pp 766- 793). Missouri: Elsevier.</p> <p>(Specific portions are taken from Box 27-4)</p> <p>Fitzgerald, K. (2011). Instructional methods and settings. In Bastable, S. B., Gramet, P., Jacobs, K. & Sopczyk, D. L.(1st Ed.), <i>Health Professional as educator</i> (419-461). Boston: Jones and Bartlett Learning</p>
WEEK 9 & 10 Conclusion and recap.	<p>The conclusion would rewind through all the material taught so far.</p> <p>The learners will have to go through an examination to determine their capability to function independently.</p>		

Predicted outcomes

1. If the trainees are assessed for their learning styles, then the trainer would be informed about what modalities to use for the majority of the class.
2. If the trainer uses different patterns to teach the topics in class, then there will be active learning.

3. If a carefully chosen experience is provided to the learners in the class, then sufficient observation and reflection can take place.
4. If adequate reflection occurs then the students can form more explicit concepts based on practical situations.
5. If clearer concepts are developed, then the student will be able to engage in better problem-solving.
6. If there is better problem solving, then there will be a productive group discussion where useful peer feedback is given from one student to the other.
7. If there is better peer feedback, then there will be better instances of reflection.

Conclusion

After the 10-week program, the trainee would be able to deliver services to ASD children. They will continue to report and be supervised by the OT of the NGO or the community hospital. Each week of the course aims to steer the minds of the learners towards active learning of the concepts. Different approaches have been researched to enable optimal learning during the period of this course.

CHAPTER FOUR – Evaluation Plan

Program Scenario and Stakeholders

In a vast country like India, problems in a community have multiple factors for their existence. Innovative solutions that simultaneously address these multiple issues would be more effective to alleviate the affected communities. The problem that *'Autism Toolkit: An online training program for laymen in rural India'* aims to solve is two-fold. The first problem, 1 in every 750 children in India, is being diagnosed with Autism Spectrum Disorder (ASD) (Raina et al., 2017) (Chauhan et al., 2019). A large number of these children, especially those outside the urban areas have no access to evidence-based intervention. There is a shortage of center-based services where skilled therapists can meet this colossal need (Divan et al., 2015). The second problem arises from 1 in every ten children in India have dropped out of school due to various reasons. Most often, the cause is financial, and children contribute to the families' income, by going to work early. Later, when these children become young adults, they are not able to secure better-paying jobs due to a lack of education (Gouda & Sekher, 2014). The resulting problem is one of unemployment, underemployment and lack of opportunity in a labor market (Mondal, n.d.).

To address the shortage of skilled healthcare workers, the World Health Organization recommends a method of "task-shifting" in high demand rural areas in low-and-middle-income countries. The specific aim is to redistribute tasks amongst a health force team to manage shortages in health workers. In this method, highly qualified health workers, move particular tasks to those who have fewer qualifications. These laymen are

trained, yet over a shorter period and are more available in the community (World Health Organization, 2008).

The '*Autism Toolkit: An online training program for the laymen in rural India*' aims to provide intervention to children with ASD in rural parts of India through training laymen or non-specialized workers (NSWs) using the principles of task-shifting. The World Health Organization (WHO) identified task shifting as a way of creating physician extenders to deliver non-specialized interventions to remote or underserved communities. The program involves engaging a few volunteers (OTs) to prepare and perform online training sessions to the laymen gathered at a familiar place in in the community. This program is culturally-sensitive while attempting to maintain standards of active learning. A formative program evaluation will help the author and stakeholders analyze the goals achieved.

The program activities also focus on addressing the WHO's Sustainable Developmental Goals (SDGs) through implementing the strategy of task shifting in this training program. The specific SDGs addressed are:

- Goal 4: Quality Education
- Goal 8: Decent Work and economic growth
- Goal 9: Industry, innovation and infrastructure
- Goal 11: Sustainable cities and communities

Table 4.1*Case Scenario*

Devansh is a 4-year-old boy referred to the local NGO for intervention by the psychiatrist in the community hospital. The staff at the NGO can provide therapeutic intervention for the 'more common' disability, i.e., cerebral palsy. The centre runs like a school for the disabled children of the community. Devansh has specific needs. Due to his affinity for fast food, he has put on much weight; he is also afraid of water.

One day at the NGO, he had a meltdown as his shirt got wet and the staff would not let him disrobe in the middle of a class. He was then 'threatened' by the teacher with water, as he didn't want to get wet. Devansh in attempt to run away from the water ran out the door of the classroom. When the staff member, a lady, chased him and restrained him, he caught hold of her hair, very tightly. Another member of staff came to the rescue. He started to run with the staff's hair in his hand! Finally, when he let go, the two were separated, and the child went home.

During the staff meeting, the majority decided that the child was unfit for a classroom setting as he demonstrated a lot of 'harmful behaviour'. Hence, the child's class time reduced from attending the class for 4 hours, five days a week to 2 hours, once a week.

The Project Overview

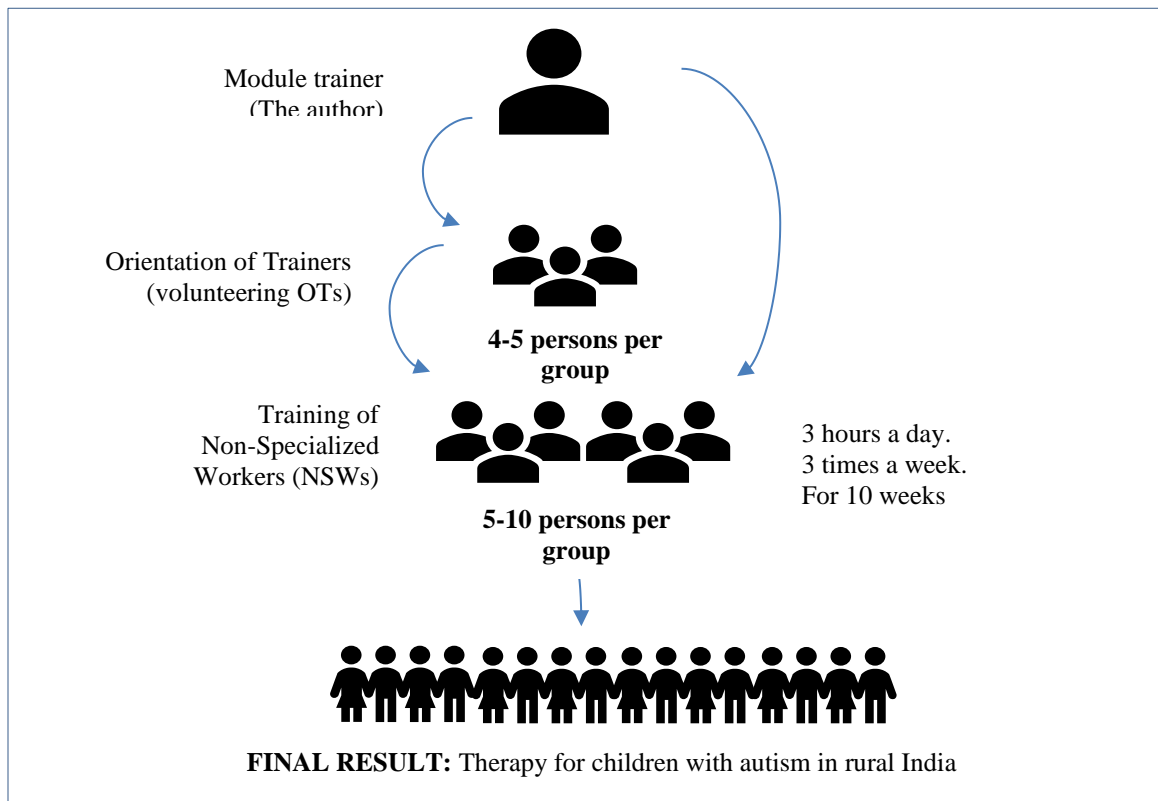
The Autism Toolkit training program is educational after which the trainees would provide intervention to children with ASD in rural India. The existing NGOs in India would benefit from this training to cater to the needs of the children with Autism

and their families with evidence-based intervention. In the case scenario presented, if there were better training to handle this situation, the staff would have been able to guide Devansh better toward more appropriate behaviors. Instead, due to a lack of proper training, two staff members were hurt, and the child's intervention (or class time) was reduced.

The format of the Autism Toolkit online training program, as illustrated in Illustration 4.1, will be delivered as live class sessions. Participants in the rural area will gather at a common place where there is an internet connection. Hindi will be the medium of instruction.

Illustration 4.1

Training process flowchart



The program will gather in a common area for the participants, such as in the local NGO or school or community college. Initially, the author will be involved in training. There can also be other OTs (as volunteers/ part-time trainers) who can help to teach the laymen. The plan is to train and guide the first few groups of NSWs to workplaces, where they can gain experiences and become competent trainers themselves.

Vision for the Program Evaluation Research

This program evaluation research design is to understand the effectiveness of the training program. Dissemination of the results would benefit the trainees, trainers and other stakeholders who are investors (both one-time and regular), employers of the NSW at an NGO or a community hospital.

Short term vision and goals:

1. To understand if the trainees feel equipped enough to be able to carry out the intervention.
2. To understand if the training was successful.
3. To evaluate if the usage of language (Hindi), for the training, as appropriate.
4. To understand if the examples used to teach concepts were understandable and culturally relevant.

Long term vision and goals:

1. To expand the training to NGOs in other parts of Northern India where the spoken language is Hindi.
2. To translate and modify the training material to other languages and cultures so that it could benefit NGOs in South India as well.

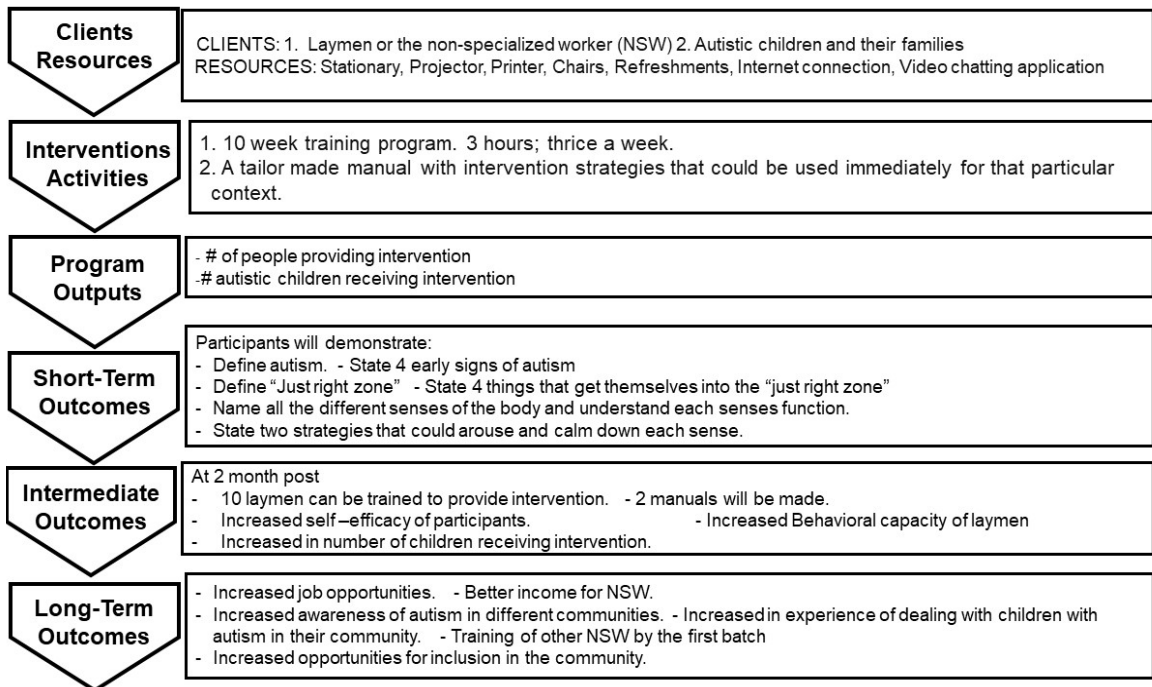
3. To apply for an AOTA/ WFOT certification for the course so that the trainees have a recognizable document for better chances for employment.
4. To modify the course to a global audience where access to intervention is limited for children with Autism in rural areas.

Program Logic Model

A program logic model is a useful tool for effectively communicating the overall program elements and objectives that shows the expected program inputs and outputs, plus short term, intermediate and long-term outcomes. It helps to understand the program aims, which is useful during the evaluation of the training program.

Illustration 4.2.

Simplified logic model for the Autism Toolkit training program.



The logic model, as illustrated in Illustration 4.2, describes that some of the main aims of the program is to reach more children living with ASD and hopefully train enough laymen so that they become trainers themselves.

Engagement of Stakeholders

The engagement of all levels of stakeholders would be vital to the evaluation plan's success. This involvement would be important as the stakeholder involvement to align the program's intent to a community needs is crucial. Furthermore, their participation in program evaluation, affirms the commitment of the stakeholders and promotes investment in future growth and sustainability of the program.

Specific strategies to engage stakeholders will ensure better compliance with the evaluation of the program. Hence, stakeholder engagement is laid out in three stages.

Stage I Categorizing Stakeholders

The stakeholders, based on their different roles or types, are separated so that a targeted approach could be used to reach out to them. The categories and the probable characteristics of the stakeholders are as follows:

- Non-specialized workers- Age: 20-50; Gender: Higher female probability
Approach: A certificate awarded once the evaluation is complete.
- Volunteering OTs section- Age: 20-50; Gender: Higher female probability
Approach: Sentiment-based and scholastic-based approach
- One-time Donors- Age: 16-29; Gender: equal probability
Approach: Incentive-based approach
- Regular Partnering section- Age: 30-70; Gender: equal probability

Approach: Incentive and sentiment-based approach

- Part-time job section (Translation/ Data Analysis involving the technical knowledge of using Tableau/ Website design and optimisation/ Marketing officer/ designer for flyers, manuals/ Accountant)- Age: 20-50; Gender: equal probability

Approach: Sentiment, incentive and scholastic-based approach

Stage II Attracting Stakeholders

The author will be using case stories and statistics on a website, or a social media platform attract the stakeholders to participate in the evaluation. An infographic will explain the program and offer a possible incentive. Targeted emails will also be used to send a message to particular persons while offering an incentive upon completing the evaluation. Possible incentives would include coupons, gift cards, free items, chance to meet famous personalities or automatic-listing into a lottery contest.

Research Design and Overview

The program evaluation research has two parts to understand, the effectiveness of the overall program implementation process and more specifically, the impact of the training program on the preparedness of the laymen to provide interventions to children with Autism in rural areas. Hence, the variables of interest are as follows:

Dependent variables:

- Understanding of concepts learnt at the training program
- Confidence to provide the necessary intervention (self-report and author-observation)

- Application of the concepts that were taught

Independent Variable

- Online training program

The design of this evaluation process is embedded in nature i.e., it includes a formative and a summative portion. The formative part will investigate the process of the program's implementation. The summative part will analyze the program participant outcomes.

The formative component will include an online survey with fixed-choice questions following the implementation of the program. Stakeholders will also participate in a focus group discussion, with open-ended questions, with trainees, trainers and other stakeholders. The summative component will be a single group posttest design using teach-back sessions after a practical experience in class. These practical experiences are given in 2-3 rounds till the trainee has reached a level of competence. These methods have been explained further below.

Evaluation Methods

As mentioned above, the stakeholders will be participating in both a focus group discussion and an online survey. The trainees are the only participants of the teach-back sessions. For the sake of a more productive evaluation process, the stakeholders are divided into

1. Trainee
2. Trainer
3. Other stakeholders. (donors, employers of the Non-Specialized Worker,

administrators of the facility that would be used for the program, and others.)

Online Survey

The stakeholders will be taken through a few quantitative questions about their experience in the program. This will be sent as links to a survey on Google Forms or Survey Monkey.

Focus Group Discussions

The author aims to conduct the focus group discussions in a manner that is comfortable for all stakeholders, including trainees, trainers and other community and professional stakeholders. This might mean that a separate meeting might need to be held, for each group, to ensure a 'safe environment' for honest feedback and conversation. These meetings will be held online via a conference call.

Introduction to the meeting. It is important to understand that the process for eliciting stakeholder input on research questions would the most crucial part would be to build a rapport with the trainees first before engaging in evaluation. This way, they might feel more comfortable to share their experiences. A brief explanation will then be given regarding the program evaluation research design and methodology, i.e., embedded design. Finally, it will be acknowledged that their perspectives and values that are brought to the project will be an essential part of the qualitative part of the evaluation.

The agenda for the sessions. The following is an overview of the objectives of the meeting. This meeting will be chaired by the author herself.

- To understand important parts of the program.

- To understand if, according to each stakeholder, all program objectives were achieved.
- To discuss the feedback from the trainees to the volunteering trainers.
- To understand, what they perceive as critical evaluation questions at the end of each session.
- To understand how they might want to use the program evaluation research findings. This may be for marketing or getting a certification or improving the way the training is delivered or choosing other topics for training based on ground-level problems, cultural-relevance, etc.
- To understand what resources, they might be willing to contribute to the research effort. This might be in terms of connections, their own expertise, among others.

Teach back sessions

Given that the NSWs are from a Hindi speaking background, surveys and questionnaires might not bring out the full essence of what was understood since a lot of the implications/perspectives of such surveys can be lost or perceived differently due to translation. Hence, the author found the teach-back method to be the ideal methodology. These sessions will be audio recorded. The sessions will be conducted online via a video-conferencing application, and they will be recorded using any audio recording software.

Research Questions for Each Stakeholder Group

The various stakeholders will be interested in different aspects of the training program as well as the general program intended outcomes. Firstly, the author is

interested to know if the trainees were able to grasp the material taught to them. Secondly, the author wants to know if the trainers were comfortable during the training program. Finally, the author is curious to understand the opinions of the other stakeholders regarding the program and its sustainability. Vital stakeholder interests will be confirmed prior to program launch and incorporated in the program evaluation. The quantitative questions will be asked through an online survey; the qualitative questions will be discussed in a focus-group discussion with the separate groups.

Table 4.2

Illustration of the potential evaluation questions to be reviewed during the stakeholder meeting.

Stakeholder or Stakeholder Group	Types of Program Evaluation Research Questions
Trainees or the NSWs	<p><i>Qualitative:</i></p> <ul style="list-style-type: none"> • Was teaching delivered at an optimal pace and intensity for learning? • Was the instruction sufficient for the participants to begin using it with clients, i.e., was it too general and not immediately applicable? • Was the program duration adequate, or should it be shorter or longer? • What other key issues or problems faced by participants were not addressed in the program? • Were they comfortable enough to ask questions to the trainers whenever they had a doubt? <p><i>Quantitative:</i></p> <ul style="list-style-type: none"> • Did participants gain needed knowledge in the language that it was delivered? • Did participants gain needed skills consistent with program goals?

<p>Trainers or volunteering OTs</p>	<p>Qualitative:</p> <ul style="list-style-type: none"> • Would the trainer have benefitted from a semi-structured manual to follow from instead of an unstructured request? • Were the concepts that were assigned too challenging? • Is the course delivery format suitable? <ul style="list-style-type: none"> ○ Hindi vs. English ○ Online vs. Face-to-face • Did external factors impede the execution of the training session? <p>Quantitative:</p> <ul style="list-style-type: none"> • Did the participants demonstrate an increase in understanding of the concept that was taught? • Did the teach-back demonstrate an increase in understanding from the training? • Are outcomes consistent with the proposed theoretical justification?
<p>Other stakeholders (Investors, employers of the NSW at an NGO or a community hospital, administrators of the facility that would be used for the program, regular-partners of the program.)</p>	<p>Qualitative:</p> <ul style="list-style-type: none"> • Do stakeholders report increase understanding of the distinctive role of occupational therapy in the provision of services relevant to the project? • Are stakeholders confident that they will be able to advocate for the program as a change agent in the community? • Are the long-term goals of the project realistic and achievable? • Will the projected increase awareness of developments in the field? <p>Quantitative/Descriptive:</p> <ul style="list-style-type: none"> • Can the research data be used to demonstrate the desired change in recipients of OT intervention as the result of the project? • In light of the health care system in rural India is the program justified based on study findings? • Will findings demonstrate that the course content matches the knowledge needed to close the clinical gap the project is addressing? • Is the delivery of the program more costly than other means of delivery? • What were the rates of program withdrawal (if any)? • What were the extra charges that the institution needed to bear to make the training program work? (a generator, better Wifi/internet connection, a new projector, and other issues.) • Were the charges presented, for training one, trainee affordable for a one-time donor?

Formative Data Gathering

For the formative evaluation, the estimated size of the group would be 7–10. There will be two data collection methods: a post-program online survey with fixed-choice questions and a focus group discussion with open-ended questions. Questions are framed to understand if the program was acceptable, comprehensible and culturally-sensitive.

As mentioned earlier, the focus-group discussions will be held separately for each of the stakeholders i.e., the trainee, the trainer and other stakeholders. These sessions will be recorded for analysis at a later date.

Formative Data Management and Analysis

Online Survey

The survey results can be transferred to a Microsoft Excel sheet to be analyzed using standard analytical techniques on Excel. Graphs and other graphical presentation methods to be used to present the results.

Focus-group Discussions

The recorded dialogue will be transcribed verbatim and may be entered into a qualitative analysis software tool such as Parallel dots, NVivo or similar software. Thematic analysis will be used to identify recurrent themes arising from the text. Response themes can be generated using a WordCloud or other simple text mining techniques to classify/score responses and bring out themes that can be coded. Next, the development of categories based on those themes and making comparisons both within and between focus group members will occur. More significant trends or concepts will be

considered with particular attention to perceived benefits and program shortcomings or unmet expectations. This information will be used to inform future iterations of the program to enhance sustainability. Descriptive analysis will be used to identify trends or themes from the fixed-choice surveys.

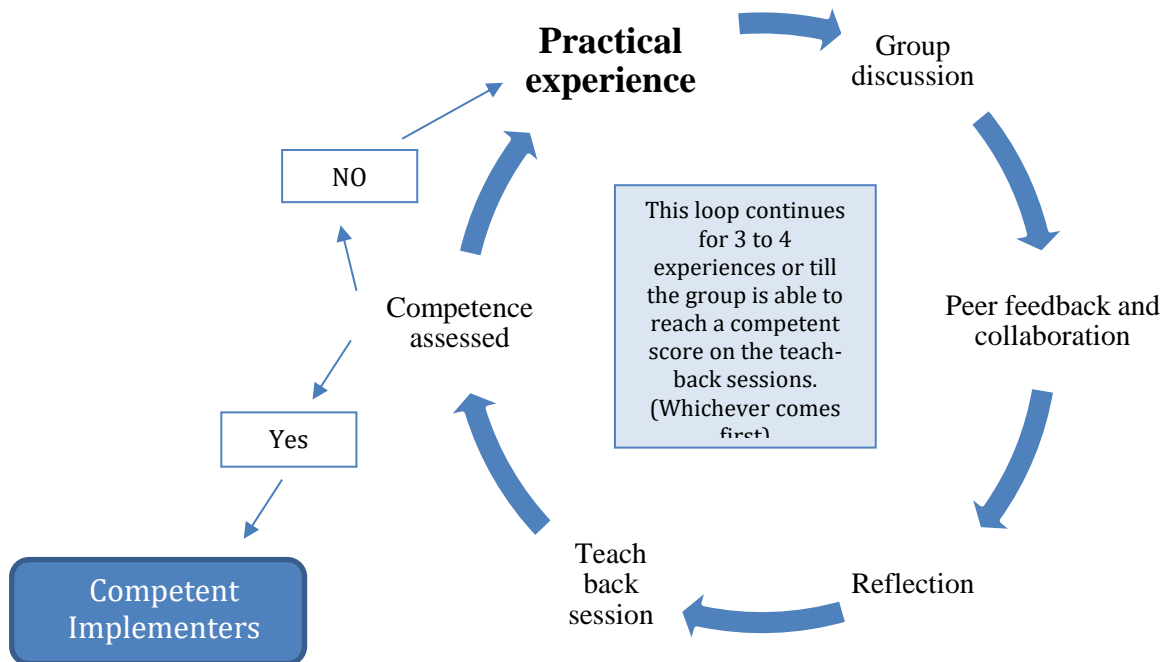
Confidentiality

This will be maintained by using codes instead of participant names in hard copies, files and spreadsheets. The database that connects the names with codes is kept in a secure document file. The videos will be stored in a secure location such as Google Drive protected with a password that only the author would have.

Summative Data Gathering

The 7–10 trainees will participate in the teach-back sessions. The figure below explains the cycle of learning until the participants reach a level of competence; this may go on 3–4 rounds across the 10-week training program.

The summative evaluation is a one-group posttest only design. As depicted in the figure above, the learner will be taken through a series of practical experiences after which they will have to do a teach-back session discussing their reflections and applications of the concepts learnt. The author decided that 3–4 rounds of experiences maybe required before a level of competency is reached. The training material is standardized, which means that all trainees will receive the same content.

Illustration 4.3*Learning process*

Note: An overview of the process of learning in the training program, based on Kolb's experiential learning theory

Relevant material/case studies will be given to students and their performance during the teach-back session is scored. For the purposes of this evaluation, it is presumed that the NSW's have little or no prior experience working with children and families with Autism; thus, there is no pretest.

The author will be directly involved in grading the students. To evaluate the knowledge, skills and abilities of the trainees following the training sessions, the author will be scoring the presenters on a scale of 1 to 10 in specific categories. A rubric will be given to the trainees prior to the presentation. These sessions will be audio-recorded for a panel review to improve reliability.

The author will be the assessor for the teach back sessions. The scoring categories for the competence assessment include:

1. Stating the background of the child and how they were able to identify the diagnosis of the child
2. Their application of concepts, as mentioned in the logic model (short term objectives).
3. Problem-solving abilities adapt concepts to the particular intervention plan relative to the child that has been assigned to them.
4. Ability to take the families situation into account when thinking about the intervention.
5. The application of culturally-sensitive strategies to provide intervention, thereby acknowledging the community's values and traditions.

Summative Data Management and Analysis

The teach-back scoring for each trainee will be entered into a spreadsheet. Quantitative data analysis would be used to analyze the scores for each test element and the total scores. In order to test the outcome of the training, nonparametric descriptive statistics using the mode, median and frequencies will be calculated using Excel. The analysis will show the author if the trainees have gained knowledge to carry out an intervention for a child with Autism. Since a pre-test was not done, the outcomes scores would be analyzed to see whether the student achieved desired competency levels. This would help understand if the training was effective at having the trainees pass the teach

back tests. By gathering that information, the author will be able to identify trends and know where adjustments to the program may be required.

Reliability will be ensured using peer reviewers (selected panel of OTs) also to evaluate the teach-back results. Once the trainee has reached a level of competence, they will be able to provide intervention under the supervision of an Occupational therapist.

Confidentiality

The audio-files will be kept in a separate secure location such as Google Drive protected with a password that only the author would have. The secure database will be maintained to use codes instead of participant names to maintain the scores of the teach-back sessions.

Disseminating the Findings of Program Evaluation Research

The author will be using a video on the program's website and social media accounts to attract more trainees for future training programs. A 2-page executive summary will also be made available for those who might want to go into details before donating to becoming a partner to sponsor a student's education. The results of the formative and summative analysis would provide an essential tool for improving the program for future trainee and illustrate to potential stakeholders that the program is essential. An expanded dissemination plan is presented in Chapter six.

CHAPTER FIVE – Funding plan

Project description

India is a developing country that has various large-scale problems that need attention in areas such as employment, providing health services in rural areas, access to education, etc. This project attempts to address aspects of two of these problems:

1. The lack of services to children with Autism who live in rural India and
2. The scarcity of opportunities to community members working in low-paying jobs in rural India, for training and a probable chance for a higher pay.

The rough estimate of children with Autism living in India being 1 in every 750 children (Raina et al., 2017) (Chauhan et al., 2019), there is a need for appropriate therapeutic services to reach them. Management of autism in a large population with limited resources, in country like India, would need a vast number of highly trained therapists to meet this need. Most of these children having no access at present to these evidence-based interventions, suffer neglect (Divan et al., 2015). There is a paucity of trained therapists and appropriate infrastructure (Kalra, Seth, & Sapra, 2005; Minhas et al., 2015) required to provide intervention for children with Austim.

In 2008, the World Health Organization (WHO) introduced the idea of ‘task-shifting’ with recommendation and guidelines. Specifically, task-shifting focuses on the redistribution of tasks amongst a health force team (World Health Organization, 2008). In this method, specific tasks are moved from highly qualified health workers to those who have fewer qualifications. The health workers are trained, yet over a shorter period and are more available in the community (World Health Organization, 2008). Providing

opportunities and training for community members to deliver services to children with Autism and their families may be an effective way to address these two pervasive problems.

This project is designed to use the community resources i.e., members of the community itself to meet a need within the community. It is made to train the non-specialized worker to deliver intervention services to the families living with an autistic child in the communities in rural India. This strategy is developed to create more instances of meaningful employment at the secondary prevention level for the non-specialized worker.

The program author will provide volunteer occupational therapists with initial training orientation to the program. These volunteer therapists will then provide the training to the individuals who want to become non-specialized workers. The orientation for the volunteer therapists is to be done via a video-calling application. The training for the non-specialized workers is to be done by the volunteer therapist trainer from their own city via a video-conferencing application. This chapter outlines the funding and resources needed for each stage of the project training and delivery plan.

Funding plan introduction

Since this program is directed to reach those living in rural India through an online program the following points were considered:

- The funding is designed to consider that the non-specialized men/women, have low resources.
- The funding plan is also designed keeping into consideration that the training

program is to be held online at a common point at the rural location.

- The trainers i.e., occupational therapists (OT) will be included on the basis that they agree to volunteer for no monetary benefit. They would only be given a certificate of participation. Thus, resources needed are minimal and may only be needed for their recruitment and certificates.

Local resources

The resources that are required for this project are as follows:

- A free video calling application such as Skype, Botim, etc. This will be most essential to connect to the trainees to the trainers. It reduces the need to travel to the rural location. The trainer could be based anywhere in the world and conduct the class.
- Consultation to create a social media marketing campaign for advertising to potential volunteers. Social media marketing is needed so the program can be explained to interested OTs with a variety of experience in dealing with children with Autism.
- Volunteering time given by the OTs. The OTs selected would need to be able to speak the local language, Hindi and be comfortable to teach in the same.
- Venue to conduct the training program at the rural location. This will mostly be at a community hospital or local Non-Governmental Organization (NGO) where there is good connectivity.
- Internet and computer hardware/software supported by a local expert. This will be needed to support any technology problems that may occur during the program.

Budget

The budget is designed to be minimum. The major investment would be in terms of the time devoted into the actual designing of the program. Resources such as space, internet, projector, computer, seating arrangements, refreshments, etc. would be organized by the hosting site. The capital budget of the whole project has been calculated to be approximately 30 lakh rupees (\$43,000 US dollars or 39,000 Euros) which includes the initial module development and the advertising. The price for every trainee would have to pay for the course is 5000 rupees. Out of this, 10% of the total fee collected per course, will be given to the hosting site i.e., the local community hospital, NGO, community college, local school, etc. To encourage the hosting site to engage more trainees and to be able to cover costs of the above-mentioned arrangements.

A break-even analysis (Appendix A) was done that includes the breakdown of the costs involved in conducting the training program. It shows that the program is expected to break-even in the 6th year of successful implementation. The three-year budget comes to approximately 39,000 rupees (\$550) which excludes the capital budget of 30 lakh rupees. Table 5.1 describes the process of the program where funding would be required. The table also shows who will be bearing the expenses; it includes the revenue and the possible expenses.

Table 5.1*Funding Guide*

Adaptation and simplification of Early Intervention (EI) strategies for children with Autism			
Done by: Author	Cost: 15,00,000 rupees (\$21,500)	Covered by: Capital budget	Expense
↓			
Plan a delivery System			
Done by : Author	Cost: NA	Covered by: Capital budget	NA
↓			
Develop a module (semi-structured)			
Done by: Author	Cost: 15,00,000 rupees (\$21,500)	Covered by: Capital Budget	Expense
↓			
Advertising- social media, flyers, banners, word of mouth			
Done by: Author	Cost: 2000/per course (\$30)	Covered by: Capital Budget	Expense
↓			
Training of Trainers - orientation to be given by the author			
Done by: Trainers (self-informed)	Cost: NA	Covered by : Trainers	NA
↓			
Training of Non-specialized workers			
Done by: Trainers	Cost: 5000 rupees per person (\$71)	Covered by: Hosting site/ Individual/Sponsor	Revenue
↓			
Venue setup including technical arrangement with internet connection			
Done by: Hosting site	Cost: 100 rupees/day (3000 per course) (\$43)	Covered by: Hosting site/Individual	Expense*
↓			
Materials needed during the course (stationary, etc)			
Done by: Individual student	Cost: 150 rupees/trainee (\$2)	Covered by : Hosting site	Expense*

*expense to be borne by the hosting site; 10% of the fees should be able to cover for the same.

Potential funding sources

Most activities of this program have been designed to be self-sufficient. However, crowdfunding this project would help to reach break-even faster. Advertising using social media, flyers, banners, word of mouth would be used to reach a wide audience. The engagement of all levels of stakeholders would be vital to the program's success.

The author has categorized the stakeholders so that targeting them would be easier. A specific approach would need to be used to engage the stakeholder appropriately. The categories and the probable characteristics of the potential funder are as follows:

- One-time Donors- Age: 16-29; Gender: equal probability
Approach: Incentive-based approach
- Regular Partners- Age: 30-70; Gender: equal probability
Approach: Incentive and sentiment-based approach
- Part-time technical- volunteer section (Translation/ Data Analysis involving the technical knowledge of using Tableau/ Website design and optimization/ Marketing officer/ designer for flyers, manuals, etc./ Accountant)- Age: 20–50; Gender: equal probability
Approach: Sentiment, incentive and scholastic-based approach

Sponsors/volunteers could be designated to one trainee where they could contribute \$75 for the training of one person. The author will be using stories and/or statistics on a website or a social media platform attract the attention of the stakeholders. Stories would be presented as a video or a few pictures. An infographics will be used to explain the program and how they get involved.

Conclusion

After the 3rd year of successful implementation, the author plans to increase the frequency of the program from 3 times a year to 6. Furthermore, the funding plan has considered that the sponsors might prefer to sponsor just one trainee. It has also tried to keep costs to a minimum, considering that the target population live in rural India where resources are low. Alternate plans have been put in place to sponsor a person, who cannot fund himself or cannot find their organization or local NGO to pay for them to participate in the program. The advertising to target potential sponsors will be done outside a training cycle as well to ensure that there is funding, if needed, for interested candidates to join the course.

CHAPTER SIX – Dissemination plan

Project description

Autism toolkit is a program that is designed to reach children with Autism and their families in rural India using a training program for laymen i.e., those who have finished their 8th or 10th grade. The problems in rural India pose a unique problem such as:

- Increase in the number of children diagnosed with Autism. (Raina et al., 2017)
- The lack of services to these children who live in rural India. (Divan et al., 2015)
- Low number of therapists, in rural India, to meet the colossal need for therapeutic intervention. (Minhas et al., 2015)

The online training program is designed to strengthen the community's resources itself to solve a problem using an effective technique called “task-shifting” (World Health Organization, 2008).

Dissemination goals

The Autism toolkit aims to equip more hands that will be available for widespread reach of intervention for children with Autism.

Long-term goals. a. In 5-years, Autism toolkit should be recognized as a credited training program that raises laymen from within a community to meet the needs of children with disability with in that community. b. It should be adopted across India in at least 10 different hospitals in 5 years.

Short term goals. a. The Autism toolkit should have at least 2–3 cycles of training each year. This could be in the same place or in a different one. b. Each training cycle should have at least 7–10 trainees who participate in the course. c. The training should lead to a

job at the hosting site or in the same community for at least three persons in each training cycle.

Target audiences

Dissemination of program information will need to be directed to multiple groups of people using a certain approach for each category. The primary audiences include the trainees or the laymen in rural India and the trainers who are the volunteering occupational therapists (OTs). The secondary audiences would include the sponsors and other volunteers.

Table 6.1

Key messages

	Category			Approach	Key messages
Primary audiences	Laymen / NGOs/ community colleges (trainees)	Age: 20–50	Gender: Higher female probability	Sentiment and fact-based approach	<ul style="list-style-type: none"> - Need for more hands to meet the need. - Better job opportunities examples
	Volunteering OTs (trainers) (from OT colleges, OT colleagues, OT associations in India)	Age: 20–50	Gender: Higher female probability	Sentiment-based and scholastic-based approach	<ul style="list-style-type: none"> - There is a neglect of children with Autism in rural India - Data from previous cycles; effectiveness of the program - An OT can now be a part of the effort to help out by just taking a few classes without travelling.
Secondary audiences	One-time Donors	Age: 16–29	Gender: equal probability	Incentive-based sentiment-based approach	<ul style="list-style-type: none"> - To support one person to take part of the course it would be \$75

	Regular Partnering section	Age: 30–70	Gender: equal probability	Incentive and sentiment-based approach	- A regular donation to support one person every course cycle. - Reduced taxes
	Part-time job section - Translation/ - Data Analysis (Tableau) - Website design and optimization/ - Marketing officer - designer for flyers, manuals - Accountant	Age: 20–50	Gender: equal probability	Sentiment, incentive and scholastic-based approach	- Need for more hands to meet the need. - There is a neglect of children with Autism in rural India - Data about effectiveness of the program

Note: The specific approach and key messages for each group that will be used is mentioned in for each group.

Sources and Messengers

The influential people for each category will be decided based on the group and where the group predominately is located i.e., either north or south India. For this project the author will approach Ms. Jubin Varghese, who is a psychologist and manager of a few rural community-based projects across North India. She has also co-founded Engage Disability which is a network of professionals across India who work for persons with disabilities. Ms. Varghese will be able to speak to the laymen of the community and the volunteering OTs. Another key person is Mr. Sanjeev Padankatti, the head of the occupational therapy department in Christian Medical College, Vellore, India. He would be instrumental in inspiring students and lecturers of the college to participate in this venture. Also, Dr Sam David, who is the contact person between different rural hospitals across India (north and south) at Christian Medical college. He will be key in networking

with the different rural hospitals who might benefit from the program. Finally, Mr. Michael Peter, a Data Analyst will be approached for support with web design, data analysis, marketing, etc. The above-mentioned people would be interviewed and video-recorded (with consent) to also speak to both the primary and secondary audiences.

Dissemination Activities

For primary audiences' flyers, social media, advertisements, WhatsApp messages/group, emails to key persons will be used to reach out to them. For the secondary audiences a social media page will be created that would be linked to a website where donations or part time job applications will be sent to.

Table 6.2

Dissemination activities

	Activities	Order	Person assigned
Primary audiences	Written information		
	Flyers	I	Part-time designer/ author
	Brochure	I	Part-time designer/ author
	Electronic media		
	Video-tape	I	Part-time videographer/author
	Website	II	Part-time designer/ author
	Social media	III	Author
	Person-to-person contact		
	Briefing	I	Author (via video calling/phone call)
Meeting	II	Author (via video calling/phone call)	

Secondary audiences	Written information Flyers Brochure			
		I	Part-time designer/ author	
			I	Part-time designer/ author
	Electronic media Video-tape Website Social media			
			I	Part-time videographer/author
			II	Part-time designer/ author
			III	Author
	Person-to-person contact Briefing Meeting			
			I	Author (via video calling/phone call)
			II	Author (via video calling/phone call)

Note: The above are the order of events and who will be responsible for the activity.

Budget

The dissemination budget for this project is nominal. The allotted expenses would be approximately 2000 rupees \$28 (US) per course. The internet charges for the duration of each course cycle and the initial briefing would amount to 500 rupees (\$7 US). The total dissemination costs are included in the funding plan in Chapter 5.

Evaluation

The effect of the dissemination would be measured by the number of inquiries for both trainers and trainees, number of likes (or shares) on social media, number of views on social media, conversion rate (from likes to views to registration).

Conclusion

The purpose of Autism toolkit is to increase the number of hands that are providing intervention in rural India for those children with Autism. The dissemination plan is designed to use existing networks and social media to ‘spread the word’ about the program and what it offers. The program addresses important societal goals that are congruent to the key stakeholder objectives. The involvement of stakeholders and promotion of the program’s aims and long-term goals, for success of the program will be pivotal.

CHAPTER SEVEN – Conclusion

The main aim of this project to improve accessibility of service to children with Autism Spectrum Disorder. The ability of this program to be able to adapt to the different communities it hopes to serve, is engrained in the ‘DNA’ of the project. With the right approvals and strong collaborations this project is a promising addendum to any rural community health program.

As mentioned earlier the program aims to equip the trainee to be able to provide intervention for children with ASD. Within the collaborating organizations such as Christian Medical College (CMC), Emmanuel Hospital Association (EHA) and Anugrah Project, there will be many opportunities for the trainees to get jobs within different community projects aimed to reach the children with ASD and their families. EHA itself has 40 community projects with 400 non-professional workers (Emmanuel Hospital Association, 2018).

Currently this program has accounted only for communities whose native language is Hindi. As the program keeps growing, the author hopes to be able to translate the content into different languages and recruit OTs who can speak those languages as trainers. The author hopes to reach these communities with evidence-based intervention techniques so that these places are not left behind when the world is running forwards in leaps and bounds in providing medical services far and wide. Regardless of circumstance, with the advance of technology, courses of this manner show great promise of a better world where none are neglected.

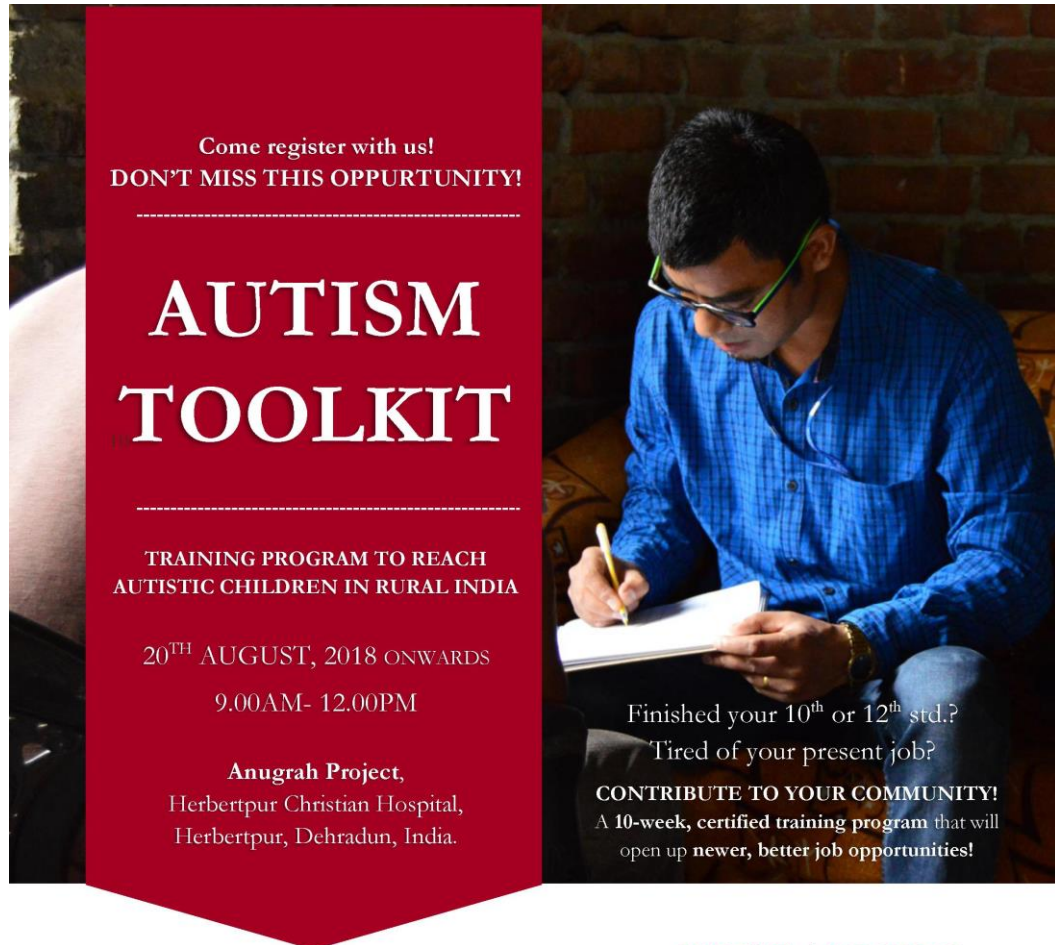
APPENDIX A – Break-even Analysis

Amounts shown in Rupees		
Revenue		
Price per NSW participant	5,000.00	
Average volume per course	7	
Number of times conducted in a year	3	
Total sales per course		35,000
Total Sales per year		105,000.00
Amount to be given to the hosting site per course		3,500
Amount to be given to the hosting site per year		10,500
Variable Costs taken by the hosting site		
Venue setup per course	3,000.00	
Supplies per course	1,050.00	
Variable costs per course	4,050.00	
Total Variable Costs per year		12,150.00
Number of times conducted in a year	2	
Total revenue for hosting site per year	(1,100)	
Gross Margin for the author		94,500.00
Fixed Costs Per Period		

	Advertising per course	2,000.00	
	Internet costs per course	500.00	
	Total fixed costs	2,500.00	
<hr/>			
Not recurring	Initial Module Development	3,000,000	
	Gross revenue		92,000.00
	Net Profit (Loss)	1st year development	(2,908,000.00)

APPENDIX B - Dissemination Posters

For Trainees (with registration form QR code):



Come register with us!
DON'T MISS THIS OPPURTUNITY!

AUTISM TOOLKIT

TRAINING PROGRAM TO REACH
AUTISTIC CHILDREN IN RURAL INDIA

20TH AUGUST, 2018 ONWARDS
9.00AM- 12.00PM

Anugrah Project,
Herbertpur Christian Hospital,
Herbertpur, Dehradun, India.

Finished your 10th or 12th std.?
Tired of your present job?

CONTRIBUTE TO YOUR COMMUNITY!
A 10-week, certified training program that will
open up newer, better job opportunities!

With the increase in the number of children diagnosed with **Autism (1:750)**, the need to deliver services to those affected is now more than ever before.

For communities such as yours, the amount of services is limited due to scarcity of therapists. Hence, we are offering this course to train you to deliver intervention, like a therapist, to these families who have children living with Autism along with the experienced therapists.

The job title that you could apply for after this course would be that of a **'therapist aid'** to work with the **community hospital and NGO.**

This course is also open to those who are currently working in an NGO, however, feel the need to **develop their knowledge** on the subject. By the end of the course, you would have the knowledge and the skills to be able to effectively deliver intervention, under the guidance of an occupational therapist.

If you need help with finances, don't hesitate to write to us at info@autismtoolkit.org

WHAT ARE YOU WAITING FOR?

Sign up today!

- 1: Scan the QR code.
- 2: Fill up the form
- 3: Wait for us to get back to you!



Those who complete the course, have a higher chance of getting a job offer from the hospital and/or the NGO!

For other stakeholders:



Did you know that 1 in 750 children live with Autism in rural India?

Autism Toolkit

An online training program for laymen in rural India
Esther Zachariah's doctoral presentation

Zoom meeting:
<https://bostonu.zoom.us/j/karenjacobsotergo>
Time: 7.45pm GST
27th April 2020

**BOSTON
UNIVERSITY**

APPENDIX C – EXECUTIVE SUMMARY

Introduction

One in every 750 children in India live with Autism Spectrum Disorder (ASD) (Raina et al., 2017) (Chauhan et al., 2019). This is a rough estimate. These numbers may be due to greater awareness of the disorder, broadening of ASD diagnostic criteria, lower age at diagnosis and diagnostic substitution (Raina et al., 2017). Management of ASD in a country like India, which has a large population with limited resources, needs a vast number of highly trained therapists (Divan et al., 2015). At present, most of these children having no access to these evidence-based interventions suffer neglect (Divan et al., 2015). For each child who lives with Autism, a family gets affected too. These families struggle to understand how to help their child (Minhas et al., 2015). Children with ASD generally require a combination of therapies and interventions to address their individual constellation of symptoms. However, the existing awareness and care for disorders like ASD is very primitive and sparse due to the paucity of trained therapists and an appropriate infrastructure especially in rural areas (Kalra, Seth, & Sapra, 2005; Minhas et al., 2015).

Autism Toolkit: An Online Training Program for the Laymen in Rural India is designed to reach children with ASD and their families in rural India using a training program for laymen i.e., those who have finished their 8th or 10th grade.

In 2008, the World Health Organization (WHO) introduced the idea of ‘task-shifting’ with recommendation and guidelines. Specifically, task-shifting focuses on the redistribution of tasks amongst a health force team (World Health Organization, 2008). In

this method, specific tasks are moved from highly qualified health workers to those who have fewer qualifications. This project is designed to use the community resources i.e., members of the community itself to meet a need within the community. The program is designed to train the non-specialized worker to deliver intervention services to the families living with an autistic child in the communities in rural India. An online training program has been designed to strengthen the community's resources itself to solve this problem (World Health Organization, 2008). An online platform was chosen to make this method more accessible.

The author realized that there was a great resource that could be used right from the community itself to meet this need. These are community members who may be looking for better job opportunities. 1 in every 10 children have dropped out of school due to various reasons (Gouda & Sekher, 2014). These individuals may benefit from and contribute to a possible solution that would incorporate task shifting principles.

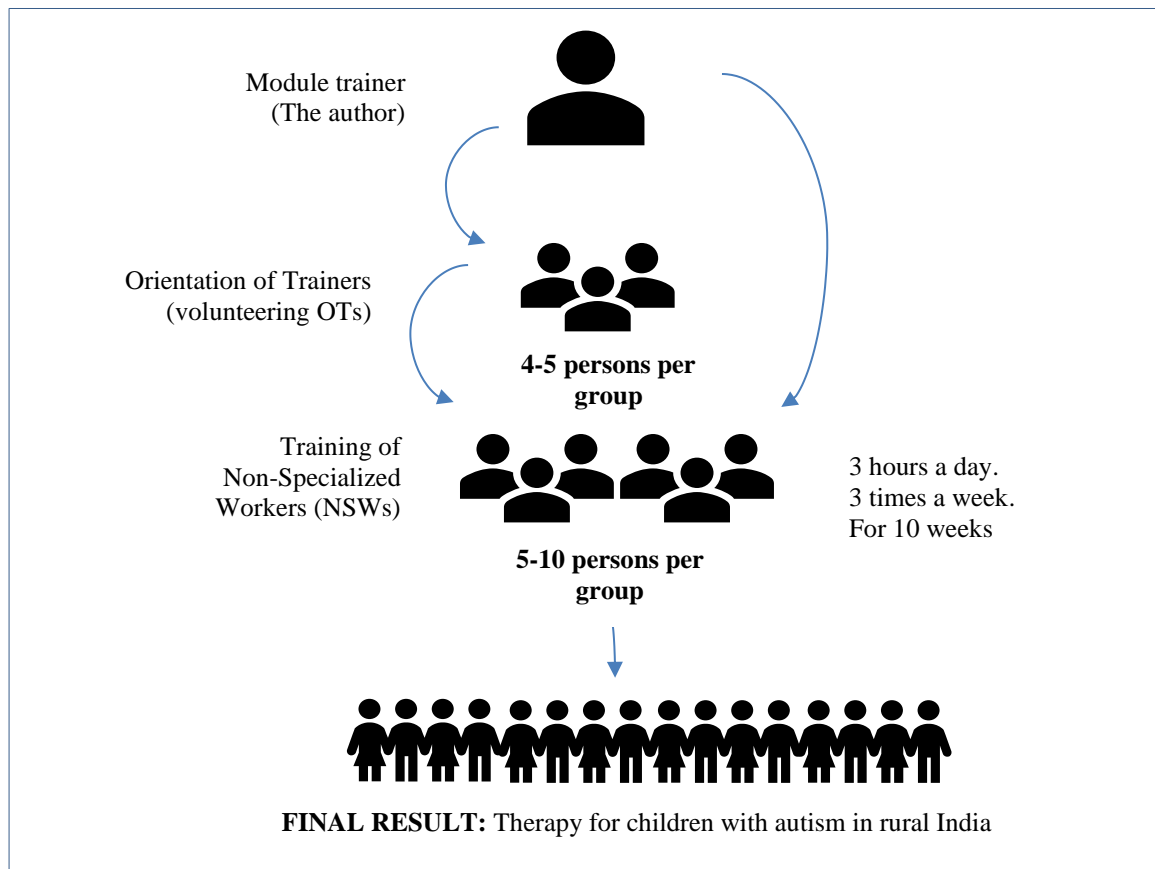
Project Overview

The *Autism Toolkit: An online training program for the laymen in rural India* is designed to be entirely online. The program author will recruit volunteer OTs, to become trainers, based on their ability to teach in Hindi. Volunteer occupational therapists will be given initial training and orientation to the program. These volunteer therapists will then provide the training to the non-specialized workers. The orientation for the volunteer therapists is to be done via a video-calling application. The training will be done from their own city via a video-conferencing application.

The program is to be delivered as live class sessions. Participants in the rural area

will gather at a common place where there is an internet connection. The course will need to be delivered in Hindi. The live class session will allow for discussions and a chance to answer questions. The trainers will need to keep in mind the culture of the participants to be able to tailor the lessons to the group.

Figure: *Schematic of the program*



Once the trainees have successfully completed the course, they will be sent to the community to provide intervention to the children designated to them. This strategy is developed to create more instances of meaningful employment at the secondary prevention level for the non-specialized worker.

The module. The trainees will be given a module that will support their intervention programs with the community they serve. The program is theoretically grounded on the principles of learning that were laid out by David Kolb's Experiential Learning Theory. Moreover, the modules will be designed to recognize these cultural differences within each community as values and cultural mindsets will vary in different communities (Kalra et al., 2005),.

In their article, Yamazaki & Kayes (2004) mention that they found cross-culture learning methods can be used as learning opportunities themselves. They state that a transactional approach to cross-cultural learning will lead the person to learn as they adapt to various cultures. Trainees in this program can work together with the volunteer OT to adapt western intervention programs for children with ASD to their particular context i.e., rural India. This situation can hence be used a way to teach learners of this program to adapt intervention themselves rather than giving them "adapted information". This way the author would be able to get a universal program, grounded on available interventions for children with autism, that is constantly adaptable to the place where it is being taught. Hence, each group of learners will have a guided semi-structured instruction manual, as an end product, to keep using after the course to implement the program.

The Pilot Program

A pilot program was run with the staff in a Non-Government Organization (NGO) in Herbertpur, India. An e-survey was conducted among a few community members. It was found that their understanding of Autism was low. However, they were interested to

get trained to deliver services, if there was a chance to a better job. Although there are taboos around disability in rural India, the survey showed the author that individuals were willing to help out and learn.

A video calling application called BOTIM was used to deliver a 1.5-hour long training program. The topics were kept simple and illustrations were taken from their own cultural surroundings to make it relevant. The pilot program did not include a manual; it was more a discussion and interactive-teaching session.

The feedback from the program was positive. The following feedback has been translated from Hindi. “... *many of the participants felt that they wanted more sessions such as this. We were able to ask doubts whenever we didn't understand. We felt comfortable.*” This not only shows their readiness to learn but also that the use of Hindi made the locals more comfortable to participate in the teaching session.

Financials

Expenses are designed to be minimum. The major expense will be the time devoted into the actual designing of the program. Resources such as space, internet, projector, computer, seating arrangements, refreshments, etc. would be organized by the hosting site. The capital budget has been calculated to be approximately 30 lakh rupees (\$43,000 US dollars or 39,000 Euros) which excludes the initial module development and the advertising. The price that each trainee would pay for the course is 5000 rupees (\$65). Out of this, 10% of the total fee collected per course, would be given to the hosting site i.e., the local community hospital, NGO, community college, local school, etc. This is to encourage the hosting site to engage more trainees and to be able to cover costs of the

above-mentioned arrangements.

Conclusion

Different approaches have been researched to enable optimal learning during the period of this course. After the 10-week program the NSW would be able to deliver services to ASD children. The author of this program hopes to be able to reach out to both the participants of this course and the children who would benefit from the intervention being administered. The NSWs would continue to report and be supervised by the OT of the NGO or the community hospital. The costs have been reduced keeping in mind that the NSW would have low resources to fund themselves. Some other efforts would be taken to attract donors to sponsor one or a few students based on their choice.

APPENDIX D – FACT SHEET

AUTISM TOOLKIT

An online Training program for the laymen in rural India |
ESTHER ZACHARIAH, BOT, PP-OTD STUDENT

BOSTON
UNIVERSITY

WHAT IS AUTISM TOOLKIT?

It is an **online training program** for laymen who have finished their 8th grade.

The goal of the Autism toolkit is to provide expanded intervention to **children in the Autism Spectrum Disorder** in rural parts of India through **training laypeople** or non-specialized workers (NSWs) through task-shifting.

Task shifting involves the redistribution of tasks within a health force team. **Capacity building** programs such as task shifting, that help solve problems within each community are advantageous (DHHS, National Cancer Institute, 2005).

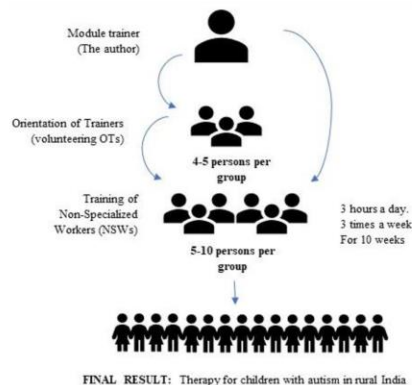
Task shifting done in South Asia suggested the real **effectiveness of such an approach for providing care related to Autism** (Bello-Mojeed & Bakare, 2013).

Research has also shown that interventions for Autism delivered by a non-specialist provider **produce benefits compared to no treatment or 'treatment as usual'** (Divan et al., 2015).

The Autism Toolkit training program is designed to **utilize volunteer Occupational Therapists** across India and the world who are able to teach simple topics using in Hindi using an online platform.

It will be done in collaboration with **hosting site** in India such as NGOs, existing community programs or rural mission hospitals.

A pilot program was implemented with the staff in a Non-Government Organization in Herbertpur, India. The program was conducted in the **local language, Hindi**.



PROBLEM #1

1 in every 750 children in India is being diagnosed with Autism (Raina et al., 2017). There is an increased demand for not enough therapists.

PROBLEM #2

According to the National Family Health Survey-3 Data, **1 in every 10** children have dropped out of school due to various reasons. (Gouda & Sekher, 2014)

SOLUTION!

WHO has suggested a method of **task-shifting** (World Health Organization, 2008) in high demand rural areas. Non-specialized workers will be to deliver the intervention.

THE CUSTOMISED TRAINING PROGRAM |

- **Culture needed to have a significant impact** on the design of the module (Kalra, Seth, & Sapra, 2005).
- Trainees in this program could be put in the same learning space to **adapt western intervention programs** for children with Autism to their particular context, i.e., rural India (Yamazaki & Kayes, 2004) that will be guided by their trainers during their class.
- This training will occur in **30 sessions across ten weeks for 3 hours a day**.
- The program is made using the **principles of Kolb's experiential Learning Theory** that comprises of both theory and practical classes (Kolb, 2015) till they reach a level of competence.
- A **teach-back session** will be conducted to evaluate their proficiency in problem-solving, adaptability of learnt topics and cultural sensitivity.
- Trainees will be given the freedom to present what they have learnt **in the local language**.
- The trainees can sponsor themselves or apply for sponsorship to Autism toolkit program team.
- Each trainee will have a guided **semi-structured instruction manual**, as an end product, to keep using after the course to implement the program.

AFTER ATTENDING THE COURSE THE CANDIDATE IS EXPECTED TO:

1. List the areas affected by a child when diagnosed with Autism.
2. List three intervention strategies for each affected area in a child with Autism.
3. Be able to demonstrate effective use of oneself during the intervention.



FEEDBACK AFTER THE PILOT

"... many of the participants felt that they wanted more sessions such as this."*

"... we were able to ask doubts whenever we didn't understand. We felt comfortable."*

*(translated from Hindi)

01: COLLABORATE AS A HOSTING SITE!

02: BECOME A VOLUNTEER TRAINER!

03: SPONSOR A TRAINEE!
THE COST FOR ONE TRAINEE IS \$75!

04: TELL OTHERS WHO MAYBE INTERESTED!

For enquiries, contact us:
autismtoolkits@gmail.com

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CURRICULUM VITAE

