

FOSTERING INDEPENDENCE: PERLIS SPECIAL TEENS CENTRE ENGAGES FAMILIES, COMMUNITIES, AND STAKEHOLDERS

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ABSTRACT

Individuals with learning disabilities are a group that requires specialized support to lead self-determined lives. In spite of this, many structural barriers hinder their participation and inclusion in society. In Perlis, Northern Malaysia, Perlis Special Teens Centre (PeSTeC) is a community-based rehabilitation program designed to increase the social and economic capabilities of individuals with learning disabilities. This study intends to explore the center's mission in engaging families, communities, and stakeholders in the pursuit of independence for the learning disabled. A qualitative research method through a case study is utilized to achieve the objective of this research. In-depth interviews with PeSTeC committee members, the program's management, and participants with learning disabilities served as the primary method of data collection for this study. The annual activity reports from PeSTeC were used to acquire secondary data. A thematic analysis is used to identify the themes that emerged in the data gathered. The findings showcased the resounding success of the community-based rehabilitation program, which effectively utilized PeSTeC's meticulously designed training modules to empower individuals with learning disabilities through a diverse range of on-the-job activities, including agriculture, food production, animal rearing, and craft-making. The program's triumph was further fortified by the proactive involvement of facilitators and the enthusiastic participation of families, local communities, and stakeholders across Perlis, particularly, and Malaysia at large. The program effectively enhanced the quality of life of the learning disabled and provided them with equality of opportunity to become contributing members of society. Future research has the potential to make valuable contributions to the existing body of literature by conducting a longitudinal study that explores the effectiveness and outcomes of community-based rehabilitation programs. By placing a strong emphasis on data collection from individuals with learning disabilities, researchers can delve deeper into the subject matter and provide a more profound understanding of the topic.

Keywords: individuals with learning disabilities, community-based rehabilitation program, Perlis Special Teens Centre (PeSTeC), economic empowerment

INTRODUCTION

According to the World Health Organization (2023), an estimated 16% of the total population, which equates to 1.3 billion people worldwide, experience some sort of disability. In 2023, a learning disability is reported as the most common type of disability in Malaysia with approximately 235,731 people registered, which accounts for 37% of the nation's recorded disabled population (Jabatan Kebajikan Masyarakat, 2023). Disability is defined as a physical or mental condition that hinders one's ability to participate in society and perform specific tasks (Centers for Disease Control and Prevention, 2020). Meanwhile, learning disability refers to a range of neurological disorders that affects the brain's ability to receive, process, store, and respond to information, resulting in difficulties in acquiring and using skills in areas such as reading, writing, mathematics, and attention (National Institutes of Health, 2023). People with disabilities experience multitudes of challenges on a daily basis including stigma, lack of opportunity, and lack of acceptance. The discrimination faced by the disabled community is deeply embedded within the societal structure, creating a cascading number of issues including limited employment opportunities, restricted support in the workplace, and reduced salaries (United Nations Children's Fund Malaysia, 2017). Consequently, this hinders them from living a fulfilling, self-determined life.

Independent living is a social movement that began in the early 1970s that emphasizes consumerism, peer support, advocacy for change, and independent living skills training (McDonald & Oxford, 1995). According to Nguyen et al. (2021), living independently does not equate to living alone. Rather, independent living pivots on self-determination, where individuals with specific impairments are given the accommodations they require to be as self-sustaining as possible. Across the world, the concept of independent living for the disabled has been carried out in several different ways including group homes, community living, co-housing, and community-based rehabilitation. In Malaysia, over 565 community-based rehabilitation centers have been established throughout the nation to provide the disabled with opportunities to be contributing members of society. Besides promoting independence, these centers encourage the integration of disabled individuals into society, allowing them to access more opportunities and services in the future.

Perlis Special Teens Centre (PeSTeC) is a community-based rehabilitation center in Pauh, Perlis with a total of 18 students, comprising 14 males and 4 females. It was established in 2019 to accommodate the growing number of disabled individuals within the state. The students of PeSTeC are diagnosed with various conditions including autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), global developmental disorder (GDD), and specific learning disabilities. The center is managed by an administrator and five facilitators with the mission to engage families, communities, and stakeholders toward independent living for people with learning disabilities. Engagement is defined as the act of partaking or being involved in a cause or activity. To engage means to reorient people into active advocates instead of being mere passive recipients of decisions determined by others. This study intends to explore the community-based rehabilitation program involving families, communities, and stakeholders instigated by PeSTeC in efforts to promote independent living for people with learning disabilities. In the succeeding section, findings of past literature alongside the gap in research are discussed. Following that, the methodology of this research is presented. Finally, the findings of the present study are reported alongside a discussion of its broader implications to the existing literature.

LITERATURE REVIEW

Various research within the literature has delved into the significance and barriers to promoting independence for the disabled community. In a study on the desire for employment among people with learning disability, 25% of the total sample studied desired to work but were unemployed. Despite acknowledging the high level of skills they possess, the structural barriers existing in the modern world hinder them from being employed. This includes the lack of transportation, scarcity of targeted job opportunities, stigma, and discrimination from the general society (Giri et al., 2022). On the other hand, people with learning disabilities that are employed reported difficulties in managing their finances due to their restricted income. This leads to difficulty in sustaining average living standards such as receiving dental and medical services. In spite of these concerns, a majority of the sample studied described the ability to live independently as rewarding (Conder & Mirfin-Veitch, 2020). These studies highlight the shortcomings that exist in the present world despite the increasing efforts to promote equality of opportunity to live independently among the disabled community.

In a study by Simões and Santos (2016), adults with intellectual disability were reported to score significantly lower in quality of life as compared to the general population. Living more independently was associated with enhanced quality of life. However, the feasibility of independent living relies heavily on the opportunities and supports provided by their environment. Therefore, it is crucial to engage families, communities, and stakeholders in the pursuit of encouraging the independence of people with disability – social and economic-wise. As stated by Samuel and Jacob (2018), no nation can claim to be civilized until every individual is given the chance to realize their full potential.

Previous research has explored the impact of communities' and stakeholders' engagement in promoting independence for the disabled community. Rosilawati and Ayu (2021) investigated the subsequent outcomes of Rumah Harapan Karangpatihan Bangkit, a community development program in Karangpatihan Village, Indonesia that centers on improving the social and economic capabilities of people with intellectual disabilities within the village. Among the activities conducted include catfish cultivation, goat farming, and handicraft making. The program, established by the village government and residents, successfully achieved the intended objective, providing them with sustainable revenue and better living conditions. In the United States, remote support services were introduced by the U.S. Department of Health and Human Services to promote in-home independence among intellectually and developmentally disabled individuals. Through technologies such as automated medication dispensers, personal assistant devices, and video cameras, caregivers were able to remotely supervise their conditions and well-being. The usage of these services allows them to lead self-determined lives in a safe environment whilst reducing the physical presence of caregivers at home (Tassé et al., 2020).

The literature on independent living among the disabled community primarily involved samples with intellectual disability, with scarce research investigating samples with a learning disability. Furthermore, independent living has been reported to improve the quality of life among the disabled population in numerous countries including the United States, Indonesia, and Portugal (Simões & Santos, 2016; Tassé et al., 2020; Rosilawati & Ayu, 2021). In spite of this, a lack of research regarding this subject matter has been done in Malaysia. Although the role of community and stakeholders has been examined in past literature, there is scarce research addressing the role of families in this issue. Therefore, this study addresses the gap in the literature by exploring the impact of engaging families, communities, and stakeholders in promoting independent living for people with learning disabilities in Malaysia.

METHODOLOGY

To achieve the purpose of this research, a qualitative approach had been implemented as it provides a deeper insight into the complex human experience in its natural settings (Cleland, 2017). A case study through in-depth interviews with PeSTeC committee members, the program's management, and students with learning disabilities was conducted to collect primary data. Two students with learning disabilities (i.e., specific learning disability and autism spectrum disorder) with the ability to comprehend and answer questions were chosen as participants of this study. Meanwhile, secondary data were acquired through the annual activity reports. Subsequent to the data collection process, a thematic analysis was conducted where the data gathered were analyzed and grouped into a number of themes.

RESULTS AND FINDING

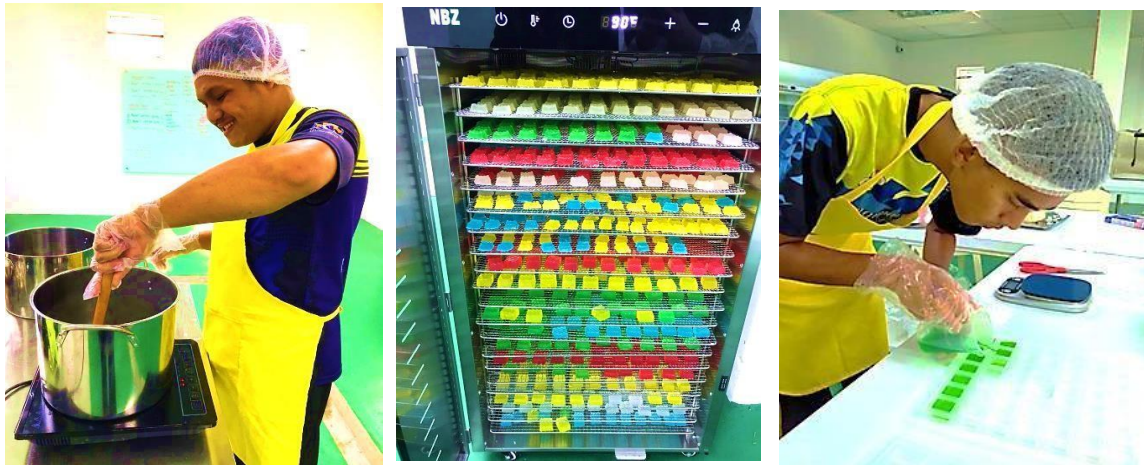
Perlis Special Teens Centre (PeSTeC) was established to accommodate the growing number of teenagers with learning disability and the lack of institutions in Northern Malaysia that support their economic and social independence. The center was founded as a non-governmental organization by the association of parents of special teenagers in Perlis, led by the chairman, Dr. Nazmin Abdullah who is a parent of two teenagers with ASD. Despite the growing efforts in Malaysia to empower the community of learning-disabled, there are still gaps in the resources and support provided to reach equality of opportunity for this marginalized community. This can be observed in the challenges that prevailed upon establishing PeSTeC. "One of the biggest challenges was the lack of funding required to set up the center and provide monthly wages for the facilitators. To overcome this, we collected preloved items from the surrounding community and put them up for sale. The income garnered, alongside the collection from crowdfunding was used to fund the center" (The chairman, personal communication, May 10, 2023). Thereafter, the center was successfully established in October of 2019.

The center began in Mata Ayer, Perlis in a rented house lot with three facilitators and nine students. When the center was first formed, it adopted modules of learning through well-established centers across the nation including Genius Kurnia and Akedemi Al-Faqeh. During the initial stages, the activities conducted include congregational prayers, Quran memorization, and daily living activities. The chairman highlighted that "Autistic individuals do well with routines. We can view this as their strength and establish a healthy routine for them in PeSTeC that they can independently carry into adulthood." Within the second year of opening, the center launched its first agricultural project through the funding granted by Angkatan Koperasi Kebangsaan Malaysia Berhad (ANGKASA). With the funds and tools provided, they were able to grow vegetables through hydroponic systems. Following this, the first food production project trailed, which was the making of meat and chicken burger patties. The harvests and products were then sold to the surrounding community and families of the students, generating revenue. According to the chairman, "Agricultural activities and food production were adopted as the primary economic activities as they cater to the students' extent of capabilities. In addition, we have also analyzed products with the highest potential to be marketed."

Figures 1 and 2: Vegetables grown by students with learning disabilities through hydroponic systems



Figures 3, 4, and 5: Dried jelly production involving students with learning disabilities



Besides empowering teenagers with learning disability, the center highly emphasizes engaging families, surrounding communities, and stakeholders in the pursuit of achieving their social and economic independence. Among the activities conducted to accomplish this mission include conferences and workshops, in-house celebrations as well as collaborations with government and private agencies to build up the center's potential. The events conducted by PeSTeC throughout the years managed to garner as many as thousands of participants across the nation, alongside an abundance of positive feedback. In addition, the head facilitator added, "When conducting events outside of the center, we would bring along several students to increase community exposure and decrease stigma against people with learning disability." After seeking grants and funding from private and government agencies throughout Malaysia, they successfully relocated to Pauh, Perlis into a more spacious facility with enhanced amenities. Furthermore, by forming alliances with institutions such as Universiti Malaysia Perlis (UNIMAP), they benefit from an array of resources, including advanced equipment and expertise offered by scholars, thereby amplifying the center's growth.

Figure 6: Booth exhibition in conjunction with Hari Bersama Murid Berkeperluan Pendidikan Khas (MBPK) Negeri Perlis

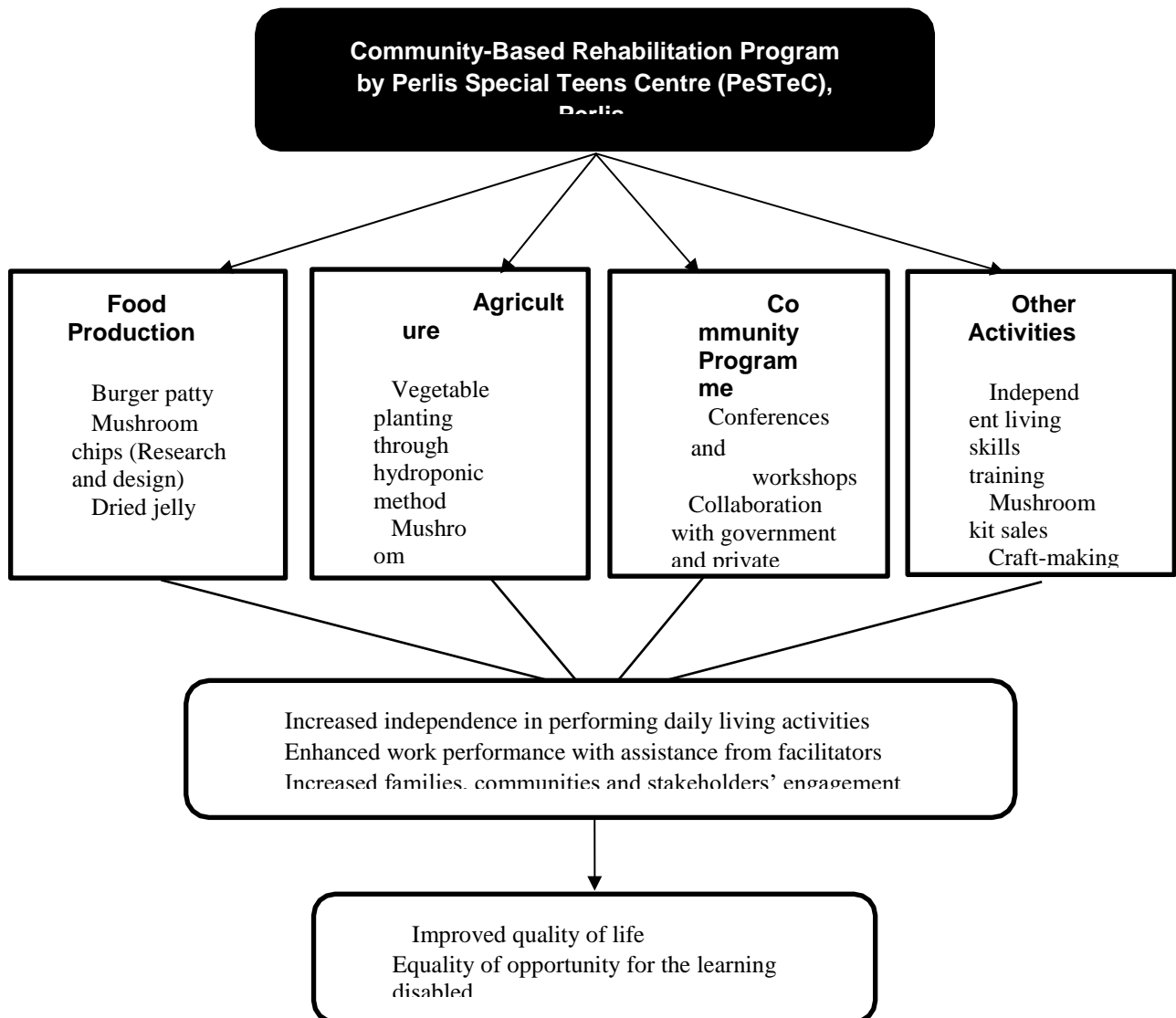


Figure 7: In-house Eid celebration with families, local communities, and stakeholders in PeSTeC, Pauh, Perlis



In the present day, PeSTeC continues to venture into various projects, including the production of dried jelly and mushroom chips, mushroom cultivation as well as animal rearing. In terms of student progress, the students exhibited consistent and encouraging advancements. A considerable number of them demonstrated improved task completion, the ability to comprehend and execute given instructions, as well as increased independence in carrying out daily living activities. In spite of these notable accomplishments, there remains a multitude of aspirations the center strives to fulfill in the future. The chairman stated, "Going forward, we plan to establish a job training center focused on the field of agrotourism, where our students can train and work there. We envision a sheltered employment program where they can work in a secure and welcoming environment, nurturing their independence."

Figure 8: Results of The Community-Based Rehabilitation Program Carried Out by Perlis Special Teens Centre (PeSTeC)



DISCUSSIONS AND CONCLUSIONS

This study is aimed to analyze the community-based rehabilitation program instigated by PeSTeC to promote independent living among people with learning disabilities. Based on the findings, several themes have emerged, reflecting the transformative journey of establishing and developing the center into its current state of growth and potential. This section analyses these themes, offering insights into the mechanisms that influenced the center's development and its broader implications.

The first theme that arose from the findings is the motivation to empower the community of learning disabled. This theme can be seen in the continuous effort put forth in expanding the center since its establishment despite numerous challenges that persist. The unwavering determination can be explained through the Social Model of Disability (Oliver & Finkelstein, 1980). Rather than focusing on an individual's impairment, this model propounds disability as a result of societal barriers and attitudes that disable the individual. This model reconceptualizes disability as a social construct and advocates on dismantling the obstacles that put the disabled at a disadvantage (Bunbury, 2019). Aligned with the principles of this model, the association of parents of special teenagers in Perlis seek to remove the structural barriers in the modern world by establishing a center that allows individuals with learning disability to achieve social and economic independence. Instead of highlighting their limitations, the chairman alongside the committee of PeSTeC seeks to create an environment that nurtures their capabilities and promotes their growth. Data obtained from interviews with the facilitators of the center reported progressive changes in the students over time. This study has proven that by providing the community of learning-disabled with equality of opportunities to participate in society, meaningful changes can eventuate.

The next theme identified is the increasing engagement of families, community members, and stakeholders in uplifting the community of the learning disabled. According to the committee of the center, this has been a continuous mission of PeSTeC as they believe collective efforts and participation is essential in order to overcome the existing structural barriers. This is consistent with the ecological systems theory (Bronfenbrenner, 1979) which illustrates how the social environment influences human development. This theory emphasizes five key ecological systems namely microsystem, mesosystem, exosystem, macrosystem, and chronosystem. In the context of this study, the microsystem, which comprises one's immediate surroundings is the center's management, families, community members, and stakeholders. Meanwhile, the interconnections within the microsystem are termed the mesosystem. In PeSTeC, the mesosystem is strengthened through the events conducted such as in-house celebrations, collaborations, conferences, and workshops. By actively engaging the aforementioned parties, the center fosters a dynamic environment with shared understanding and collective responsibility to uplift individuals with learning disabilities. Forming this cohesive ecosystem enables greater access to opportunities that broaden the center's potential and growth. This is aligned with the findings reported by Rosilawati and Ayu (2021), where the collective efforts of people in Karangpatihan Village, Indonesia successfully uplifted the social and economic capabilities of people with intellectual disabilities within the village.

The final theme from the findings is the progress and aspirations for the future of individuals with learning disabilities. Since its establishment in October 2019, the center exhibited remarkable growth across multiple dimensions including the success in venturing into numerous projects, inclining engagement from families, community members, and stakeholders, and encouraging the progress of its students. By sharing its experiences and achievements, PeSTeC aspires to inspire other centers and non-governmental organizations across the nation to empower the community of the learning disabled. This is consistent with the self-efficacy theory, proposed by Bandura (1977). It posits that behavior is governed by one's perceived self-efficacy and outcome expectancies. According to this theory, one's belief in their capabilities to help another (i.e., perceived self-efficacy) and the potential impact of their involvement (i.e., outcome expectancies) is likely to influence their decision to engage. Furthermore, besides extending its potential as a center, PeSTeC envisions a shift in paradigm where individuals with learning disabilities are given a chance to realize their full potential and become contributing members of society.

Conclusions

The qualitative nature of the present research allows the researcher to obtain a nuanced perspective into the mechanisms involved in the establishment and development of PeSTeC. This study thoroughly analyzed the community-based rehabilitation program, which actively engages families, communities, and stakeholders to promote independent living for individuals with learning disabilities. The research findings unveiled three significant themes that reflect the journey undertaken by PeSTeC to arrive at its current state of potential. It contributes to the growing body of literature on community-based rehabilitation programs for individuals with learning disabilities. Moreover, the findings shed light on the significance of actively involving families, communities, and stakeholders in promoting independent living and enhancing the quality of life for individuals with learning disabilities. The insights gained from this research can inform and inspire other centers and non-governmental organizations to adopt similar community-based approaches and foster inclusive practices. However, it is crucial to acknowledge the limitations of this study, such as the restricted number of students involved in the data collection process, which may impact the diversity of perspectives captured. Consequently, future studies should prioritize directly gathering data from individuals with learning disabilities, if applicable, to ensure a comprehensive understanding of the experiences and needs of these individuals. In addition, future studies could adopt a longitudinal method of research to observe the development and effectiveness of a community-based rehabilitation program over time.

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