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BUILT ENVIRONMENT FOR CHILDREN WITH AUTISM: PHILANTHROPY AS A SOURCE OF FUNDING

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Abstract

Built environments could be a useful help for parents of children with autism spectrum disorders (ASD) to handle the severe situation caused by COVID-19 pandemic, and to optimize the children with ASD environment fit. Lack of financial to prepare built environment for children with ASD among the public will lead to those children being misplaced in unsuitable physical and cognitive development. This paper aims to highlight the new culture in funding through philanthropy to provide a built environment for children with ASD. It is envisioned, through this philanthropical funding approach, will minimize the financial burdens of parents or caregivers. A descriptive analysis was conducted to evaluate the Socio-Demographic Characteristics of Respondents and their families' financial situation. Information was obtained on the level of behaviour on philanthropy usage in providing built environment to children with ASD. Besides, information on the families' financial conditions were also solicited since it is crucial in determining the respondents' actions and their course when seeking solutions. The findings revealed that financial situation especially after COVID-19 impacted parents or caregivers. The pandemic of COVID-19 emphasises the need for a safe and comfortable space especially for children with ASD. This research additionally notes that there exists a high level of future behavioural intention in the realm of financing the built environment for children with ASD through philanthropy funding. Therefore, this study concludes that providing built environment for children with ASD specifically at home is a useful mechanism to assist parents in handling the severe situation and optimize the children with ASD environment fit.

INTRODUCTION

Autism Spectrum Disorders (ASD) is a relatively common neurodevelopmental disorders which affects children to exhibit strong resistance to change. It is categorized by impaired social interaction, lack eye contact, communication, and the presence of stereotyped activities (Matar, Mahmoud, Razan & Mohammed, 2017). They are probably getting infected by any other age group or other normal children

and can become active agents to spread diseases especially COVID-19. Although younger age groups are less likely to get bad impacts from this disease, it is still not impossible.

Typically, children with ASD encounter challenges in establishing and maintaining interpersonal connections with their family members, friends, and strangers' people. The aforementioned behaviours can be attributed to a deficiency in maintaining eye contact, a tendency to consistently withdraw from social interactions, a lack of interest in engaging with family members, and a persistent fixation on a certain subject matter. Children with ASD have some specific needs for support such as physical support due to the difficulties in social communication, stereotyped behaviour patterns, and other specificities that come with autism. As to stop the spread of COVID-19, temporary closing of child development centres, schools, and other facilities that children with ASD attended daily can create additional tension especially to their parents or caregivers.

Built environments are obviously not exhaustive but could be a useful help for parents of children with ASD to handle the severe situation caused by COVID-19 pandemic and to optimize the children with ASD environment fit. Lack of finance to prepare built environment for children with ASD among the public will lead to those children being misplaced in unsuitable physical and cognitive development. The failure in considering the needs of children with ASD can easily result in more frequent episodes of behavioural accident and social isolation among them (Zulkarnain, Azree, & Mydin, 2019). Most of the environment can be too loud, too noisy, too fast paced, too smelly and too confusing for children with ASD (Martin et al., 2019). Thus, unable to comply with a suitable environment will lead to psychological distress not only for the children with ASD but for their families as well (Kanakri, Shepley, Tassinary, Varni & Fawaz, 2017).

Creating an atmosphere that is conducive to living demands the high allocation of financial resources, which can cause challenges for certain families, particularly those with low incomes. The financial constraints faced by families with children diagnosed with ASD can be particularly challenging due to the high costs associated with treatment and therapy, potentially impacting their overall quality of life (Fraczek & Gagat-Matuła, 2018). According to Gagat-Matuła (2021), the emotional well-being and financial stress experienced by parents can detrimentally affect the overall functioning of a child with ASD.

Hence, the present study was undertaken with the intention of identifying the socio-demographic characteristics of the respondents, and assessing the financial situation of their families. Information was obtained on the level of behaviour on philanthropy usage in providing built environment to children with ASD. A descriptive analysis was conducted to evaluate the impact of COVID-19 to the families' financial situation and level of behaviour on philanthropy usage in providing built environment to children with ASD among Muslim parents or caregivers. Some recommendations are proposed in light of the findings to provide valuable inputs to parents or caregivers and fund providers. The rest of the paper is organized as follows: Section 2 presents the literature review, followed by the research method in Section 3, the analysis of the key results, discussion and robustness checks are provided in detail in Section 4, and finally, Section 5 presents the conclusion of the study.

LITERATURE REVIEW

Autism Spectrum Disorders (ASD)

The name of autism spectrum disorders (ASD) adopted in 2013, is a neurodevelopmental disorder characterized by persistent problems in social communication and interaction, along with restricted and repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). It replaces the older terms of autistic disorder, Asperger's syndrome and other conditions envisioned on "the great continuum" of autism. Still, the defining features of the condition commonly referred to as "autism" remain essentially the same. ASD also refers to spectrum conditions that affect individuals differently to varying degrees. There are three (3) levels of ASD which are Level 3 (Requiring very

substantial support), Level 2 (Requiring substantial support) and Level 1 (Requiring support).

Although there are no official statistics of total registered individuals with autism diagnosed within all 3-severity levels in Malaysia (see, 2002), the World Health Organization, estimated that 1 in 160 children on this earth has this prevalence. Anyhow, in 2013, the Ministry of Health stated that there were 117 detected and registered major ASD cases for children from birth till 18 years old in 2011. The reported cases have increased to 170 major autism cases in 2012. Nowadays, in accordance with the advance in ASD study globally, the increase in new findings to ASD development programs has been established. Although there is no known cure for ASD, most research shows that an early intervention such as behavioural treatment and skills training programs during their childhood will enable them to be reaching the optimal development and well-being (WHO, 2019).

The Autism Society of America has defined ASD as the complex development disability that usually appears during early childhood and can affect a person's ability to communicate and interact with others. However, WHO refers ASD as "a range of conditions characterized by some degree of impaired social behaviour, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively". This prevalence usually begins since birth and tends to remain throughout life. However, in certain cases of this disorder appear in the period of the first five (5) years of life. This organisation also stated that people with ASD are usually born with similar conditions such as epilepsy, depression, anxiety, and attention deficit hyperactivity disorder (ADHD). Meanwhile, their level of intelligence is tremendously inconstant, which is in the range of low to extremely high levels.

Embracing New Normal for Children with ASD

In March 2020, the Federal Government of Malaysia announced the Movement Control Order, which is commonly referred to as the MCO, in response to the COVID-19 pandemic in Malaysia (Bunyan, 2020). In the areas of education and child support systems, the Prime Minister had instructed to implement home-based learning initiatives throughout the duration of MCO (Povera & Yunus, 2020). The temporary suspension of ASD centres, schools, and other services by the government during the MCO period has caused significant financial difficulties among parents or caregivers. After MCO, embracing new normal among children with ASD can be more challenging. This is because children with ASD commonly exhibit strong resistance to change and always the presence of stereotyped activities (Alsehemi, Abousaadah, Sairafi & Jan, 2017).

Individuals with ASD are usually easy to be in frustration, annoyance, and physical discomfort due to an environment that did not fulfil their needs (De Verdier, Fernell & Ek, 2018). Moreover, ASD students that experience sensory problems will process possible cognitive overload and executive functioning (De Verdier, Fernell & Ek, 2018). In the worst case they can become quite drowned or shut down or rather expressing. This condition is known as meltdown which can lead to "challenging behaviour" (Martin et al., 2019). Although the sensory friendly spaces for ASD are able to stimulate the learning environment, each of the ASD children requires a specific design to unlock their full potential (Zulkanain, Azree & Mydin, 2019).

During MCO, these children are encouraged to stay indoors and be safe outdoors. Children with ASD's specific facilities at home were not mostly originally designed for ASD. Most of it does not apply to the aspect of psychology, but only focuses on the functional aspect of space. Therefore, it is recommended to focus on these three (3) aspects which are building, space and technologies. This aspect has the potential to improve the life of children with ASD. The internal environments such as living environments or home environments should be reconsidered based on elements that can be designed or modified to alleviate these challenges and create an ASD friendly home (Nagib & Williams, 2017). Furthermore, ASD individuals can enhance their daily life experience (Iowe, Gaudion, McGinley & Kew, 2014).

Suitable environment leads to achieve other goals, which lie beyond but, in many ways, depend on the architectural discipline itself, such as aiding the learning process, promoting autonomy, facilitating socialization, ensuring independence or even, from a wider point of view, preserving the dignity of individuals with ASD. COVID-19 is questioning the routine of our young children with ASD, and they are called to respect rules and habits that are not always understandable for them. These changing routines could cause them profound suffering. Hence, it is important that parents, caregivers, therapists, and researchers collaborate cohesively to immediately establish a novel and efficacious environment that fosters a sense of security and peacefully for children with ASD.

Built Environment for Children with ASD

A conducive environment is crucial for the children with ASD to enable them to learn and be comfortable with the environment. It also allows them to explore and be self-motivated to do things on their own. Appropriate circumstance can affect the development of children with ASD in many aspects depending on the activities conducted. Peer group learning can contribute to an imitation of a proper social development. The study of environment plays an important role in selecting the study area in a classroom. To design the environment for children with ASD, it is important to prepare a clean, well-ventilated, and spacious areas for their activities (Noiprawat & Sahachaiseri, 2010). Having a specific reading corner or area for other activities will be an advantage. The area should be free from noises and it is a private area that are not open to outsiders that may distract the learning process.

The primary objective of creating an accommodating environment for children with ASD is to facilitate their learning and foster self-motivation. By establishing a suitable learning environment, their capacity for acquiring knowledge and skills can be optimised. The children will acquire knowledge by observing the actions of their peers, engaging in play, and extending opportunities to other children to participate and gain insights from their shared activities. Engaging in social interactions can facilitate the development of children's self-esteem and enhance their ability to adapt to societal norms.

METHODOLOGY

There are public and private autism children development centres in Melaka such as Kanner Melaka Society, Wing Melaka Society, Permata Kurnia Centre for Southern Zone Development Project, Swiss Spectrum Wellness, The National Autism Society of Malaysia (NASOM) Melaka, Gym Academy Child Development Centre and many more. This, therefore, makes it a suitable location for data collection concerning this issue. The respondents in this study consisted of parents or caregivers of children diagnosed with ASD who were aged 12 years old or below. They were registered at any children development centres in Melaka. A total of 53 respondents were included in the study. Parents or caregivers of children with ASD selected on a stratified random basis. A stratified sampling method was used to find respondent populations. Accordingly, only those who could provide the detailed information needed were selected as respondents. This is to increase the sample's representativeness of the population and decrease sampling error and sampling bias. The survey, which was conducted with the help of a research assistant, was structured into four distinct sections for completion by parents or caregivers.

FINDINGS AND DISCUSSION

A descriptive analysis was conducted to socio-demographic characteristics (Table 1), type of financial support received (Table 2), impact of COVID-19 on level of financial situation (Table 3) and impact of COVID-19 on level of financial situation (Table 4). The perspectives of the participants were closely intertwined with their financial circumstances in the present context. Moreover, the measures undertaken by the participants in their pursuit of remedies for their children's diseases were influenced by their financial circumstances. The overall results shown in Table 1 and 2, respectively.

Table 1: Demographic Characteristics of Parents or Caregivers

Socio-demographic characteristics	Frequency	Per cent (%)
Relationship		
Parents	50	94.3
Caregivers	3	5.7
Children gender		
Male	31	58.5
Female	22	41.5
Parents / caregivers age		
20-29 years	4	7.5
30-39 years	36	67.9
40-49 years	12	22.6
50-59 years	1	1.9
Educational qualifications		
PhD. / Doctor of Philosophy	1	1.9
Master	7	13.2
Bachelor's degree	21	39.6
Secondary	3	5.7
Diploma	21	39.6
Occupation		
Self-working	9	17.0
Government	28	52.8
Student	1	1.9
Housewife	1	1.9
Private	7	13.2
Not working	7	13.2

The demographic characteristics in Table 1 shows that 1.9 per cent have Doctor of Philosophy (PhD.) qualification, 5.7 per cent of the respondents have secondary education, master's degree represent 13.2 per cent of total respondents and both diploma and bachelor's degree represent 39.6 per cent. This indicates that almost all the respondents are educated enough to register their children with ASD to receive early intervention and other programs in any children development centre.

Among all respondents, the highest proportion of the respondents (52.8 per cent) mentioned that they were working with the government, while 17 per cent self-employed. Students and housewives stand for 1.9 per cent. Meanwhile the total of respondents that were not working and working with private showed 13.2 per cent. This is evidenced by the fact that the respondents who had attained the age of at least 30 years constitute 92.45 per cent. The high proportion of the respondents' age category can be as a result of their maturity in handling their special needs children specifically children with autism.

Next, a total of 58.5 per cent of the respondents is male and 41 per cent is female. A total of 94.3 per cent are parents (mothers and fathers) while the lowest proportion of the respondents (5.7 per cent) cent is caregivers (aunty, uncle, grandparents, and others). Regarding the religious affiliation of the respondents, 100 per cent were Islam. More than half of the respondents (52.83 per cent) had 3 and above of the number of financially dependent in their family. 15.1 per cent have only one and 17.0 per cent have two people that depend on their financial.

Table 2 presents an overview of the financial assistance received by parents or caregivers. The type of financial support such as Bantuan Prihatin Nasional (BPN), Bantuan Sara Hidup (BSH), Malaysia Welfare Department (Jabatan Kebajikan Masyarakat, JKM) and Geran Prihatin Khas (GPK), zakat, PERKESO and others. Out of 100 per cent respondents, almost more than half respondents (58.49 per cent) stated that they received financial support from government and other institutions (school, Islamic institution, etc.). In the meantime, 41.51 per cent stated that they did not receive any financial support.

Table 2: Type of Financial Support Received

Type of financial support	Frequency (Respondents)	Per cent (%)
Bantuan Prihatin Nasional (BPN)	15	28.3
Bantuan Sara Hidup (BSH)	3	5.7
Bantuan Sara Hidup (BSH), Jabatan Kebajikan Masyarakat (JKM)	1	1.9
Bantuan Sara Hidup (BSH), Bantuan Prihatin Nasional (BPN)	4	7.5
Pertubuhan Keselamatan Sosial (PERKESO)	1	1.9
Geran Prihatin Khas (GPK)	1	1.9
Jabatan Kebajikan Masyarakat (JKM)	3	5.7
Not received any financial support	22	41.5
Others	2	3.8
	53	**100.0**

A total of 28.3 per cent received support from BPN, 5.7 per cent from BSH, 1.9 per cent from GPK, 5.7 per cent from JKM, 1.9 per cent from zakat institution, 1.9 per cent from PERKESO and others representing special financial support from specific schools and their employers. In addition, there are respondents who received two types of financial support which is from BSH and JKM (1.9 per cent). An additional four individuals were provided with financial aid from BSH and BPN (7.5%). Despite receiving such assistance, there remains a subset of parents who continue to experience financial hardship even after the COVID-19 pandemic (refer Table 3).

Table 3: Impact of COVID-19 on Level of Parents or Caregivers Financial Situation

No.	Item	Responses					
		Yes	%	Not Sure	%	No	%
1.	COVID-19 affects my daily expenses	16	30.19	17	32.08	20	37.74
2.	COVID-19 affected my financial position	18	33.96	14	26.42	21	39.62
3.	COVID-19 affects my investment/financial savings	16	30.19	19	35.85	18	33.96
4.	COVID-19 affected my work	14	26.42	9	16.98	30	56.60
5.	COVID-19 affects my source of income	12	22.64	16	30.19	25	47.17
6.	COVID-19 affect my family financial situation	36	67.92	0	0	17	32.08

Based on the data provided in Table 3, it is apparent that the COVID-19 pandemic had significant effects on the financial situation of parents or caregivers. A significant percentage of 67.92% reported experiencing an extreme level of impact. In contrast, a significant number of the participants, specifically 32.08 per cent, reported that their financial situations have remained unaffected throughout the pandemic. The results are consistent with previous research that suggest the COVID-19 pandemic has had a significant impact on individuals' financial situation. According to the survey findings, a significant proportion of respondents (33.96%) said that their financial situation has been greatly affected by the COVID-19 pandemic. On the other hand, a slightly larger percentage (39.62%) indicated that they have not had any influence on their financial position. A smaller portion of respondents (26.42%) expressed uncertainty on the impact of COVID-19 on their financial circumstances.

Majority of the respondents, specifically 56.60 per cent, indicated that their current occupation has no impact on them. Similarly, 47.17 per cent of the respondents reported that their source of money does not affect them. The reason for this can be attributed to the fact that a significant proportion of the respondents are employed in the public sector, specifically working with government sector, comprising 52.8 per cent of the total. Approximately 30.19% of the participants acknowledged the negative impact of COVID-19 pressure on their everyday expenses and savings. In relation to daily expenses, 30.08% of the respondents expressed uncertainty, while 37.74% indicated that their daily expenditures remain unaffected. In the realm of savings and investments, of the total respondents, 33.96 per cent said that their savings had remained unaffected by the impact of COVID-19. Conversely, the remaining 35.85 per cent of respondents expressed uncertainty on the impact on their savings

Table 4: Level of Intention Behaviour on Usage of Philanthropy in Providing Conducive Environment to Children with ASD

No.	Item	Responses					
		Yes	%	Not sure	%	No	%
1.	I am more positive with the use of philanthropy	45	84.91	8	15.09	0	0
2.	I am willing to recommend the use of philanthropy	45	84.91	6	11.32	2	3.77
3.	I will continue to support the use of philanthropy	47	88.68	5	9.43	1	1.89
4.	I am willing to use philanthropy	45	84.91	8	15.09	0	0

Table 4 presents an overview of the dependent variables that have been used in the model. The dependent variable consists of the participants' responses to a range of questions that assess the level of intention to participate in charity funding in order to create a supportive environment for children with ASD. Majority of respondents have a strong inclination. A significant majority of respondents, which is 84.91 per cent, expressed a favourable inclination towards the utilisation of philanthropy. Furthermore, an equivalent percentage of respondents, 84.91 per cent, indicated their willingness to embrace the usage of philanthropy. Additionally, a substantial proportion of respondents, 88.68 per cent, expressed their intention to maintain their support for the implementation of philanthropy. Lastly, a significant percentage of respondents, 84.91 per cent, expressed their readiness to participate in the use of philanthropy. This study demonstrated that parents or caregivers are open to receiving assistance from philanthropic organisations in order to provide a suitable physical living environment for children with ASD.

The findings indicate that the financial circumstances after the COVID-19 pandemic have exerted an influence on parents or caregivers, despite the fact that a majority of the participants reported receiving financial assistance from governmental and non-governmental sources. There are numerous valuable recommendations for creating supportive physical living settings for children with ASD both prior to and beyond the unprecedented COVID-19 outbreak. According to a study conducted by Lowe, Gaudion, McGinley, and Kew (2014), it was discovered that children diagnosed with ASD exhibit a unique perception and interaction with their physical surroundings. This study specifically highlights their sensory sensitivity and unusual interests as key areas of focus.

The utilisation of appropriate architectural design solutions is crucial for enhancing the environment of children with ASD, taking into consideration both the physical and psychological aspects (Reeves, 2012). The occupational sector that is closely associated with individuals with ASD should also prioritise certain design characteristics, such as imagination, communication, social interaction, sensory difficulty, behaviour, and safety (Arnaiz Sánchez, Segado Vázquez & Serrano, 2011). Furthermore, Kanakri, Shepley, Tassinary, Varni, and Fawaz (2017) proposed the inclusion of acoustical design considerations in the context of meeting the needs of children with ASD. Specifically, they emphasised the importance of regulating ambient conditions and noise levels. The decline in sensitivity to noise results in heightened sensitivity to differentiating sound from ambient noise.

The presence of a living-built environment has the potential to create a positive impact on the sensory environment, thereby benefiting individuals with ASD. This impact extends to the physical space itself, which can contribute to enhancing positive factors for children with ASD (Pomana, 2017). Furthermore, the influence of the living-built environment on individuals with ASD encompasses their performance, perception, and behaviour (Nagib & Williams, 2017). The provision of an appropriate environment has the potential to enhance the overall quality of life. According to Bock, Borders, and Probst (2016), the inclusive environment has the potential to improve both social and intellectual skills. The study conducted by Khare and Mullick (2009) suggests that an emphasis on inclusion and well-being in the built environment can indirectly enhance performance, particularly in relation to prosthetic support for functional performance.

CONCLUSION

The responsibility of having children with ASD is risking parents and caregivers' wellbeing and quality of life. In fact, having a child with ASD often leads them to a journey that is riddled with interfaces with various professionals and specialists, and endless research for better understanding and seeking out various alternatives. These issues will lead to a heavy financial burden of raising a child with ASSD. Due to COVID-19 pandemic, some of them also affected financially. This study confirms the effect of COVID-19 on the financial situation of parents or caregivers. Although with the lack of financing, preparing built environment for this child is crucial. Pomana (2017) states that equipping children with ASD with tools to cope with their circumstances can contribute to their ability to tolerate and navigate ASD-related challenges. The utilisation of built environments can serve as a valuable resource for parents of children with ASD in manoeuvring the challenges presented by the COVID-19 epidemic. These environments can help optimise the compatibility between children with ASD and their surroundings, hence facilitating a more conducive and supportive environment for their development and well-being.

The result of this study found that the financial situation during COVID-19 has had an impact on parents or caregivers although more than half of the respondents had received financial support from governments and others. The level of future behavioural intention in financing their children with ASD built environment through philanthropy funding is also high. This study concludes that, providing conducive children with ASD's physical environments at home could be a useful mechanism to assist parents in handling the severe situation caused by COVID-19 pandemic and to optimize the children with ASD environment fit. Most of the parents willing to receive support in order to embrace a built environment to children with ASD after the novel COVID-19 pandemic using philanthropy. Future study may extend this study by considering all children development centres in Malaysia. It will be interesting to conduct a comparative study looking into development centres based on the fund provider and its region. Different fund provider may have different environment setting or practices that may lead to different results.

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CONFLICT OF INTEREST

The authors affirmed that there is no conflict of interest in this article.

AUTHOR CONTRIBUTION

The contribution of the co-author in the article such as: Author 1 planned and implemented the field work, prepared the literature review, and manage the writeup of the whole article. Meanwhile, Author 2 and 3 wrote the research methodology, involved in collecting, entering, and analysing the data, and review the whole article. Author 4 carried out the interpretation of the results and review the writeup of the whole article.

AI GENERATIVE DECLARATION

The author declares that generative AI tools were not used in the creation of this article, except for text paraphrasing and cross-checking references. The author assumes full responsibility for the accuracy, integrity, and final content of this work.

RESEARCH ETHICS STATEMENT

The author(s) declare that this study did not involve any human biological samples or data, or animal subjects. Consequently, formal ethics committee approval and informed consent were not required for this research.

DATA AVAILABILITY STATEMENT

The data supporting the findings of this study are available from the corresponding author upon reasonable request, subject to institutional and ethical requirements.

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