

Waqf Based Autism Spectrum Disorder Care Centre Framework: Adapting Typical Structure for a Public-Private Partnership

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Abstract

The need for developing low cost one stop center for ASD patients is a crucial component of the growth equation between normal parents and parents with ASD children who are struggling financially. Unfortunately, the government cannot afford to spend on big investment projects for ASD's patients due to budget limits. In addition, worldwide economic recovery is slowing down and the increasing cost of living also worsening the condition. Despite that, basic wellbeing needs should maintain a right direction growth similar the demographic growth to satisfy the ASD population's demand. The insufficiency of fit resources brings a gap to this balancing rule by leaving the way to imbalance within the society which can put the stability of states in danger of loss, harm, or failure. Therefore, all sectors can play an important role by collaborating with the government to create partnerships in searching for enough sources. Waqf is suggested to be part of the solution for financing problems. The paper focuses on parents with ASD issues, but its conclusions are of broader interest. Institutions, public service and industries involved in ASD need to seek new configurations of collaboration and combine all available public and private experts to circumvent this financial problem.

Keywords: Autism Care, Autism Spectrum Disorder, Autism Well-Being, Waqf

Introduction

The concept of public-private partnership (PPP) is a strategic collaboration between two or more entities in the government sector and the private

sector for the improvement of economic and social development. This partnership is important to reach the social indicator in ensuring holistic development. Its implementation in Malaysia may provide many benefits to the government and the public as a whole. This type of shared prosperity is a commitment to achieve sustainable growth and equitable distribution in the nation. Malaysian government has worked hard in ensuring sustainable and inclusive economic growth in the longer term. Recently the Shared Prosperity Vision of 2030 a new government blueprint released by the government of Malaysia for the period of 2021 to 2030. The main objective of this blueprint is to increase income of all ethnic groups focusing mainly on the B40. This goal can be achieved only if the plan is executed efficiently especially in balancing the economy between the society (Shared Prosperity Vision 2030, 2019).

There is a great opportunity by shared prosperity using waqf based funding to help the parents of children with autism to increase their financial support in Malaysia, thus decreasing the possibility of not sending their children to get early intervention. Waqf can play a significant role in upgrading the needs of autistic children and their parents especially for lifelong learning. The function of waqf as Islamic financial instrument is proven in enhancing well-being program generally and specifically for improving the quality of life of the Muslim (Hisham, 2013). The collaboration between waqf institutions and the government in developing private autism care centres need to be explored as one of the methods in social development between these two institutions. Although waqf based autism care centres may provide low service price rate for low income

parents, this institution still can provide sustainability financial income from these partnerships though the normal rate fee will be charged for those who can afford such services. Hence, the need for a Waqf Based ASD Care Centre Public-Private Partnership Project that combines intervention programs such as healthcare and special education programs is a key component of the growth equation between normal parents and parents with ASD children who are struggling financially.

Usually, waqf assets are used for economic and social purposes, in which one of the popular uses of waqf is for funding healthcare centres. For example, 50 hospitals in Egypt, Fatih Hospital in Istanbul, Myint Myat Phu Zin clinic model in Myanmar, Waqf An-Nur hospital and clinic in Johor Malaysia, and USIM health specialist clinic in Negeri Sembilan, Malaysia. Besides healthcare, the most popular usage of waqf is in educational sectors. According to Mahamood and Ab Rahman (2015), the role of waqf is significant in providing financial assistance to their communities as well as strengthening their academic quality. Waqf has a huge potential to help students both directly and indirectly. This had been supported by (Harun, Possumah, Shafiai, & Noor, 2014a) who revealed that waqf can be used in financing education.

Phenomenon of interest

From the prospect of ASD development, family members are the first and primary caregiver for them. They provide the external support and frequently become the primary source of support for both autistic children and adults (Happé & Charlton, 2012; Howlin & Moss, 2012). However, parents have difficulties dealing with their child's behavior and emotional problems during development learning processes from birth. The development includes inter alia the physical, emotional, social and intellectual aspects. The critical condition occurs when the children require specific requirements. This responsibility is risking their well-being and quality of life (Gardiner & Iarocci, 2012) both positively and negatively (Cridland, Jones, Magee, & Caputi, 2014). The more severe the ASD children are, the more decreasing parents' well-being have been reported (Barker et al., 2011; Grayand Holden, 1992; Jones et al., 2013; Pozo et al., 2013). They

were susceptible to falling mental health, higher levels of worry, depression, anxiety and stress.

In Malaysia, autism issues are getting less attention from the public due to lack of experience and knowledge on handling them (Suhaili & Siti, 2014). Such a gap may lead people to bully the autistic children which are not healthy for their physical and mental development. As a result, they tend to isolate themselves, have low self-esteem and prefer to be in their own world rather than interacting with other children or other people. As a consequence, the autistic children's development on social and communication skills is stagnant. In addition, parents found to have refused to send their autistic children to suitable intervention centres for early intervention programs because of the working commitment as well as the unstable financial condition since the therapy requires high expenses. This kind of centre incurred high fees according to the level of autism experienced by the child such as level 3 (requiring very substantial support), level 2 (requiring substantial support) or level 1 (requiring support). Moreover, the child might need to attend several types of therapies such as occupational therapy, physiotherapy and speech therapy. Although the general hospital prepares all these types of therapies, however, it is still not enough for the autistic child to progress well.

Besides, the low-income level parents experience lack of support from the government in terms of the expenses for therapy that lead to burden and unstable financial condition. This is the main reason whereby the parents refuse to send their child to the respective centre for the early intervention program. Other than that, the standard operating procedures to register or join the early intervention program is very hard due to many certifications needed as evidence that the child is confirmed having this disorder. A lot of the stress of this comes from the fact that all these things will lead to a heavy financial burden of raising an autistic child. Moreover, the children require more special attention and early intervention and all these cost money.

The incidence of ASD has increased in recent years. It is challenging and a lot of patience is needed in order to take care of an autistic child. Some of the parents have more than one autistic child and that absolutely requires a lot of physical, mental and emotional strengths. Therefore, it is

very important to ensure the public are aware and sympathize about autism care and well-being to support parents of children with autism emotionally and mentally. This is so as awareness and knowledge of these disorders is still poor among the public in general and the health and education community in particular.

There has been a steady increase in the number of children diagnosed as having an ASD. This shows that parents are aware about this condition and know that their children must get early intervention and have the right to access quality education to continue living such as a normal person. Consequently, demand for services to meet the needs of these children and their families has increased (David, 2003). The Malaysian government has taken measures to assist parents of children with autism by providing them with financial support through monthly allowance. However, these allowances are insufficient to finance the services for the treatment, therapy, medicine and transportation for children with autism (Hisham, 2013). Meanwhile, private special needs education is expensive and inclusive education where special needs children are able to learn together with neurotypical children is hard to come by. Therefore, waqf initiatives would be another great alternative for the parents to increase their financial condition thus, enable them to send their children to specific centres for early intervention.

Having a child with ASD often leads parents to a journey that is riddled with frustration, difficult decisions, interfaces with various professionals and specialists, and endless research for better understanding and seeking out various alternatives (Salomone, Leadbitter, Aldred, Barrett & Byford, 2018). A lot of the stress of this comes from the fact that all these things will lead to a heavy financial burden of raising an autism child. Parents and families of children diagnosed with autism encounter a wide range of unanticipated and unavoidable personal and financial costs of raising children with autism. Household costs often include loss of employment and loss of income due to increased needs of the child in addition to large out of pocket expenses (Togneri, 2014). Parents should be given an alternative rather than sending their child to general hospital, which is once a month therapy, to other private centres that offer affordable and lower fees and more frequent

sessions of therapy (Tipton & Blacher, 2013). Hence, parents of children with autism should be assisted to ensure they can sustain their economic condition without having to resign from their job.

Frequent and consistent therapy can encourage the autistic children to progress well and easily for the therapist to follow up the children's physical, mental and emotional development so as to prepare them for school or college (Rose, 2014). By doing so, it can improve the quality of life of the children with autism and their families. Moreover, parents of children with autism will no longer experience problems due to the high increase in household expenses. This is because the cost of raising a child with autism is three times higher than raising a typically developing child (Lee, Odom & Loftin, 2007).

Literature review

Public-Private Partnership (PPP) refers to the cooperative arrangement between two or more public and private sectors, typically of a long-term nature (Hodge & Greve, 2007; Roehrich, et. al. 2014). The Malaysian Prime Minister Department (2009) states PPP as a "form of cooperation between the public and private sector whereby a stand-alone business is created, funded and managed by the private sector as a package that encompasses construction management, maintenance and repair works as well as replacement of public amenities comprising buildings, infrastructures, equipment and facilities" (PPP Unit, Prime Minister Department, 2009).

This shared prosperity concept between the proposed institutions may solve this large economic gap which indirectly increases social well-being (PPP Unit, Prime Minister Department, 2009). Social well-being is the extent to which you feel a sense of belonging and social inclusion; a connected person is a supported person in society. Social well-being is achieved when we have good relationships, social stability and peace. The parents of children with autism must be helped to increase their financial condition to be more stable in order to ensure they could send their children to suitable early intervention centres. This is because this type of centre incurred high fees according to the level of autism of the children as well as depends on the frequency of therapy needed. Children with ASD should be well-trained since

young because they are incapable in managing their daily routine as well as expressing their feelings effectively. Other than that, a lot of knowledge and sharing sessions will be given to the parents when they actively send their children to the early intervention centre. Meanwhile special education in a fit environment is one of the keys to increase their quality of life.

A state of mental, physical and social well-being has contributed to the strengthening of individuals, family and communities. Well-being is utilized for both economic and social purposes. This concept had been introduced by the World Health Organization (WHO) in 1948. Throughout the years, the well-being concept has sustained its place as the main agendas for many governments and policymakers around the world (UNICEF, 2007). In the meantime, individual well-being has recently been considered to become indicators of

family well-being. As a matter of fact, family well-being has taken interest in providing children’s welfare, and recognition of the role in nurturing children’s well-being (Wollny et al., 2010).

Conceptual framework

The collaboration between waqf institution and government structure can be quite complex, involving various parties including customers which are parents with ASD children. Figure 1 below illustrates the proposed PPP structure process. This proposal idealized after taking into account the benefits such as socio-economic impacts, value for money and cost savings to the government, quick delivery of the project and service enhancement and lastly increased level of accountability, efficiency and effectiveness (ESCAP, 2008).

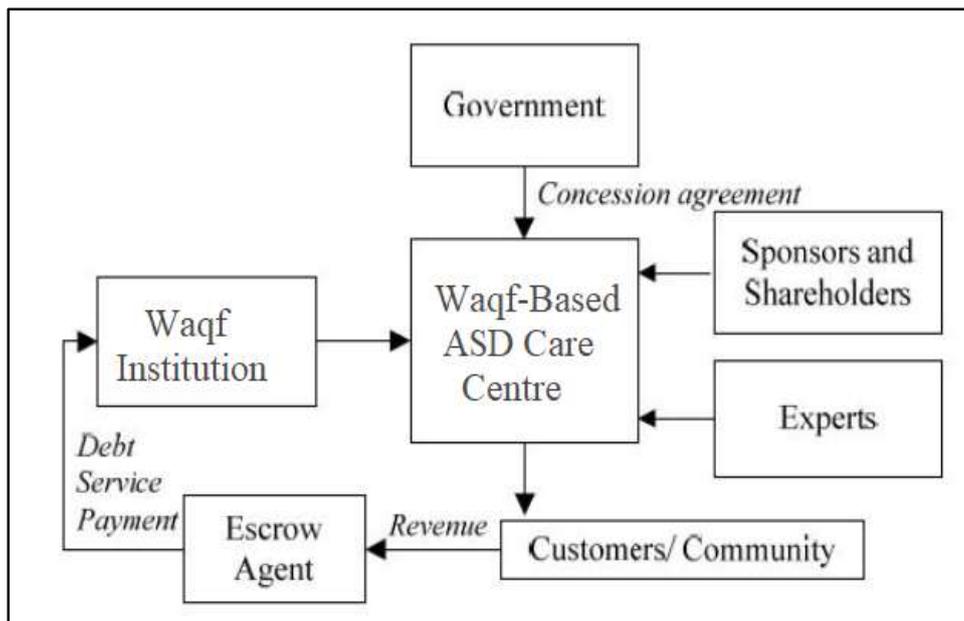


Figure 1: Proposed Waqf Based Autism Spectrum Disorder Care Centre Framework in Enhancing Social Well-Being
 Source: Adaptation of a typical structure of a PPP project (ESCAP, 2008)

The above framework was adapted from The Economic and Social Commission for Asia and the Pacific (ESCAP). This commission serves as the United Nations’ regional hub promoting cooperation among countries to achieve sustainable development. ESCAP supports governments in Asia-Pacific in implementing measures to efficiently involve the private sector in infrastructure development. Developing case

studies is part of this effort and promotes exchange of experience among the countries of the region (ESCAP, 2016). The success is proof that this model can be used to sustain ASD institutions using waqf resources.

One of the successful PPP projects using this framework in Malaysia is Case 5: The case of Port Klang. Another cases are stated below:

Case 1	Traffic Demand Risk The case of Bangkok’s Skytrain
Case 2	Efficiency Gains / The case of Water Services in Manila
Case 3	Mobilizing Private Funding / The case of the National Highways of India
Case 4	Land Value Capture Mechanism / The case of the Hong Kong Mass Transit Railway
Case 5	Port Klang
Case 6	Automatic Fare Collection System: The Case of Manila

Referring to the earlier framework, escrow agent normally represents a financial institution that is appointed by the project company and the lenders for managing an account called escrow account. Meanwhile, the expert in the framework represents various participating groups in this PPP project including teacher, therapist, engineers and architect (designer), contractor (builder), operator and others (ESCAP, 2008).

The role of the architects and engineers are mostly during the first phase i.e. in creating the fit building environment in this center. From the physical and psychological aspect, the suitable architecture solution should be utilized to enhance the environment and lives of people with ASD (Reeves, 2012). The related occupational sector should move into this direction too in focusing on imagination, communication, social interaction, sensory difficulty, behavior and safety as design criteria for ASD (Arnaiz Sánchez, Segado Vázquez, & Serrano, 2011). By focusing on the inclusion and well-being for people with ASD in the aspect of built environment (Pomana, 2017), this may indirectly increase their performance especially in the aspect of prosthetic support for functional performance (Khare & Mullick, 2009) and equipped ASD with the tool to tolerate with ASD circumstances (Pomana, 2017).

At this juncture, the proposed Waqf Based Autism Spectrum Disorder Care Centre Framework in Enhancing Social Well-Being is simply a preliminary study. An actual empirical study will be conducted within the ASD’s potential stakeholders as highlighted in the framework. It is envisaged that the outcome of a refined framework will assist the governmental agencies and parents

alike to improve the well-being of the ASD children.

Conclusion

The welfare of the ASD children have long been the responsibility of their parents with the assistance from the government allowance. This preliminary conceptual study highlighted that through a Private-Public Partnership (PPP), a synergy of Waqf institutions, government, experts, communities and parents with ASD children, a Waqf Based Autism Spectrum Disorder Care Centre Framework in Enhancing Social Well-Being can be materialized. Such a framework will assist ASD parents and government alike in addressing the lack of financial resources to maintain the welfare of the ASD children. The proposal will be further extended to an empirical research in the near future with the inclusion of stakeholders mentioned in the proposed framework.

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References

Anil, S. & Sanjeev, R. (2014). Awareness and Knowledge of Autism Spectrum Disorders among Primary School Teachers in India. *International Journal of Health Sciences and Research*, Vol.4, Issue 4, 80-85.

- Adewale, A. A., Nurul, A. I., Siti, S. H. (2016). An Empirical Investigation of the Determinants of Cash Waqf Awareness in Malaysia. *Intellectual Discourse*, 501-520.
- Crane, J. L. & Winsler, A. (2008). Early Autism Detection: Implications for Pediatric Practice and Public Policy. *Journal of Disability Policy Studies*, Vol. 18, Issue 4, 245-253.
- David, P. (2013). Providing an 'Autism-Friendly' Service for Children with an Autistic Spectrum Disorder in a Short-Term (Respite) Care Setting. *Journal of Integrated Care*, Vol. 11, Issue 1, 38-45.
- ESCAP (2008). A Primer to Public-Private Partnerships in Infrastructure Development. Transport Policy and Development Section, United Nations Economic and Social Commission for Asia and the Pacific (ESCAP).
- Harun, F. M., Possumah, B. T., Shafiai, M. H. B. M., & Noor, A. H. M. (2014). Empowering Higher Education Institution: the Role of Waqf - Malaysian Perspective. In *Proceedings of the Australian Academy of Business and Social Sciences Conference 2014* (pp. 1–13).
- Herrman, H., Saxena, S., & Moodie, R. & World Health Organization (2005). Promoting mental health: Concepts, emerging evidence, practice: A report of the World Health Organization. Department of Mental Health and Substance Abuse in collaboration with the Victorian Health Promotion Foundation and the University of Melbourne.
- Hisham, Y. (2013). Waqf History and Legislation in Malaysia: A Contemporary Perspective. *Journal of Islamic and Human Advanced Research*, Vol.3, Issue 6, 387-402.
- Lee, S., Odom, S. L. & Loftin, R. (2007). Social Engagement with Peers and Stereotypic Behavior of Children With Autism. *Journal of Positive Behavior Interventions*; Austin. Vol. 9, Issue 2, 67-79.
- Matar, A. A., Mahmoud, M. A., Razan, A. S., Mohammed, M. J. (2017). Public Awareness on Autism Spectrum Disorder. *Neurosciences Journal*, Vol.22, Issue 3, 213-215.
- Mahamood, S. M., & Ab Rahman, A. (2015). Financing universities through waqf, pious endowment: is it possible? *Humanomics*, 31(3), 354–371. <http://doi.org/10.1108/H-02-2015-0010>
- Public-Private Partnership Unit, Prime Minister Department. (2009), *Public Private Partnership (PPP) Guideline*.
- Rose, C. (2014). Parenting Stress, Coping Styles, and Posttraumatic Growth in Parents of Children with an Autism Spectrum Disorder. *The Chicago School of Professional Psychology*, ProQuest Dissertations Publishing. 3621509.
- Salomone, E., Leadbitter, K., Aldred, C., Barrett, B. & Byford, S. (2018). The Association between Child and Family Characteristics and the Mental Health and Wellbeing of Caregivers of Children with Autism in Mid-Childhood. *Journal of Autism and Developmental Disorders*. Vol. 48, Issue 4, 2018, 1189-1198.
- Suhaili, M. S. & Siti, S. A. R (2014). A preliminary study: Awareness, Knowledge and Attitude of People towards Children with Autism. *Proceedings of Social Sciences Research ICSSR 2014*, 322-332.
- Shared Prosperity Vision 2030, (2019). Prime Minister's Office of Malaysia, Government Policies. adapted from: <https://www.pmo.gov.my/2019/10/shared-prosperity-vision-2030-2/>
- Tipton, L. A. & Blacher, J. (2013). Brief Report: Autism Awareness: Views from a Campus Community. *Journal of Autism and Developmental Disorders* Vol.44, Issue 2, 477-483.
- Togneri, L. T. (2014). Parenting Stress, Psychological Well-Being, Depression, and Anxiety in Parents of Children with and Without Pervasive Developmental Disorders. *Alliant International University*, ProQuest Dissertations Publishing. 363505