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Waqf as An Alternative to Government Expenditure in Financing Autism Spectrum Disorder Children's Cost: Experience from Malaysia

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Abstract

The waqf is derived from Arabic roots verb 'waqafah' which means to stop or retrain. Waqf in Islamic law means; holding a certain asset and distribute only the usufruct for certain philanthropy. Waqf is defined by Islamic jurists as the holding of assets that are beneficial and physically lasting in order to be given as charity. Waqf assets and properties are prohibited from being used out of its specific objective. Waqf also can be defined as non-negotiable property dedicated to charitable purposes. Hence, in general waqf can be explained as dedication of some properties for certain philanthropy in the name of Allah S.W.T. Waqf is applied to non-perishable properties from which benefit and usufruct can be drawn without the property being consumed. The properties cannot be sold, transferred or inherited due to its perpetuity characteristics. Once the asset is declared as waqf, it will remain as waqf forever. It is a great opportunity if the waqf-based funding can help the parents of children with ASD to increase their financial support. Along with the rising of ASD children, the Malaysian government currently introducing a lot of initiatives to help the parents to get and receive early intervention and implementing various financial supports for them. This huge number of expenditures had concerned the government and despite the huge amount used by government, parents are reported to still been burden of financial stress in proper raised children with ASD. They usually have a variety of obligation expenditure to meet their unique needs such as special the treatment, therapy, medicine, education, and others. This obligation is continuously since there is no known cure for ASD. Parents of children with ASD children reported significantly less satisfaction with the assistance they have received since their child's diagnosis. About 93% of parents of children with ASD did not receive adequate financial support for their child's therapy. Moreover, parents should be given an alternative rather than sending their children to the general hospital, which is once a month therapy session, to other private children development centres that offer affordable and lower fees and more frequent sessions of therapy.

Therefore, this study contributes to a better understanding of waqf as an alternative to help the parents of children with ASD and reduce the government expenditure.

Keywords: Autism Spectrum Disorder, Children, Government Support, Waqf

Introduction

Waqf, in the Arabic language, means to stop, contain, or preserve. In Islamic terms, waqf refers to a religious endowment i.e. a voluntary and irrevocable dedication of one's wealth or a percentage of it - in cash or kind (such as a house or a garden), and its disbursement for shariah-compliant projects (such as mosques or religious schools) (Hisham et al., 2013). Moreover, waqf has contributed to the strengthening of the Islamic practices within the Muslim communities. Usually, waqf assets are used for economic and social purposes, in which one of the popular uses of waqf is for funding health care centres. In addition, waqf is a continuing charity with a long-lasting positive outcome and a great opportunity to donate and gain the reward. Allah's Messenger Muhammad said,

"When a man dies all his good deeds come to an end except three: ongoing charity (Sadaqah Jariyah), beneficial knowledge, and a righteous son who prays for him".

Having a child with Autism Spectrum Disorder (ASD) often leads parents to 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 of this will result in a significant financial burden of having an ASD child. Parents and families of children diagnosed with ASD encounter a wide range of unanticipated and unavoidable personal and financial costs of raising children with ASD. Household costs often include loss of employment and lost income due to increased needs of the child in addition to large out of pocket expenses (Togneri, 2014).

Instead of sending their children to a general hospital for once-a-month therapy, parents should be offered the option of sending their children to a private centre with more cheap and frequent therapy sessions (Tipton & Blacher, 2013). That is why parents of children with ASD should be assisted so that they can maintain their financial situation without having to resign from their jobs. Frequent and consistent therapy session can help to encourage the children to progress well and make it easier for the therapist to monitor their physical, mental and emotional development in order to prepare them for school or college (Rose, 2014). By doing this as well, it can help to improve the quality of life of children with ASD and their families. Moreover, parents of children with ASD will no longer experience a problem due to the high increase in household expenses. This is due to the fact that raising a child with ASD is three times higher than raising a typically developing child (Lee, Odom & Loftin, 2007).

Literature Review

The Role of Waqf

Waqf differs from other types of philanthropy in that it has a perpetual nature, making it a long-lasting charity. The main objective of waqf is to be used for religious purposes, such as the construction of a mosque or other religious institutions like schools and Madrasah. Waqf, in addition to providing continuing benefits to donors and beneficiaries, has a significant

impact on Muslim economics by reducing poverty and promoting economic development. Furthermore, waqf has the ability to help countries cut their government spending.

Poverty Alleviation

Poverty is a universal problems and poverty alleviation become one of the priorities in Malaysia (Mohd Umar et al., 2012). The Malaysian Government have developed and implemented several programs since 1970, for instance the New Economic Policy (NEP) implying growth with equity (1971-1990), National Development Plan (1991-2000), National Vision Plan (2001-2010), "Program Pembangunan Rakyat Termiskin" (Program PPRT), Amanah Ikhtiar Malaysia (AIM, 1987), TEKUN (1998), "Program Pemulihan Sikap Keluarga Termiskin" (SIKAP PROGRAM) and "Program Makanan Tambahan Keluarga Termiskin" (MTKT Program). The latest program designed by the government was in 2012, Malaysian government has allocated RM2.6 billion for its Social Safety Net program called "Bantuan Rakyat 1 Malaysia" (BR1M). All Malaysian with monthly income below than RM3,000.00 are eligible to receive BR1M. This program aims to reduce poverty and improve the quality of life of the nation. This program has been successfully implemented and continues up till now.

Another approach to combat poverty is through charity and one of the effective way is undoubtedly a long-lasting charity such as waqf (Hosseini et al., 2014; Saifuddin et al., 2014). One of the ultimate purposes of waqf, as evidenced by its continued success over the last decade, is to eliminate poverty among Muslims. Because of its flexibility, cash waqf is gaining popularity among Muslims in Malaysia and has shown to be a useful tool for poverty reduction (Umar et al., 2012). In fact, cash waqf allows those in the middle class to donate. Mutawalli can invest the cash obtained in the real estate sector or any Islamic-based investment vehicle. Profits from the investment will be handed to the poor to help them escape poverty. Numerous studies have identified waqf as an instrument for poverty alleviation. Furthermore, Amuda et al (2015), found that proper implementation of cash waqf has reduced the poverty rate among the less privilege in Nigeria. Moreover, Saifuddin et al., (2014) conclude that increased cooperation between public, waqf institutions and government entities might become a solution to the centuries-long problem of poverty.

Economic Development

Besides helping in poverty reduction, *waqf* also can be used to enhance the economic development (Budiman, 2014). The main objective of the development of *waqf* assets is to help the poor and needy by providing a basic need that they cannot get access. There are numerous developments of *waqf* assets all over the world for the purpose of social, economic, education and religious. The development of housing, schools, hospitals, shop houses and mosques are among the most common types of development of *waqf* assets (Almanaseer & Bashar, 2014). It has been proven by the history during the Ottoman Empire, *waqf* and the economy was highly connected in a positive direction which given advantages to the Muslims. A better management of *waqf* assets leads to positive growth of the economy (Mohamad Suhaimi, Ab Rahman, & Marican, 2014). In addition, the development of housing project helps the needy to own house with lower price from the market and eventually eradicating the number of homeless. Moreover, the participation of the private sector as an investor or collaborator will also affect the national economic progress (Budiman & Kusuma, 2011). More job opportunities also have been created for the development of *waqf* assets.

Reduction of Government Expenditure

On the other hand, *waqf* benefits to the government through reducing government expenditure (Budiman & Kusuma, 2011). Utilization of *waqf* will lead to provision of numerous essential public amenities such as health and education services that can be provided without additional cost to the government. This is because the development of the public services can be fully financed by *waqf*. As a result of the reduced need for government borrowing, there will be a reduction in government spending and a reduction in the budget deficit. From an economic standpoint, when government spending reduced, the interest rate reduced as well. Riba (interest) can also be eliminated by lowering the interest rate. (Cizakca, 2014). Hence, this is consistent with Islamic economic principles, which forbid transactions involving riba (Cizakca, 1998; Samad et al., 2005).

For instance, a study by Ambrose et al (2015) found that *waqf* has the potential to reduce Malaysia government expenditure. Through *waqf* financing, most of the Federal Government expenditure, the remaining tax revenue can then be allocated to pay down debt. This finding was in line with previous studies by (Budiman & Kusuma, 2011; Çizakça, 2013; Shirazi, 2014) which stated that the funds available from *waqf* can be used to replace the government expenditure. Indirectly, government can reduce the budget deficit, thus leading to better distribution of income, reduction in interest rate and enhancing economic growth.

Waqf Development on Health and Education

Another role of *waqf* is to help the social development of Muslim through health and education. Health and education are important in ensuring the continuity and sustainability of Muslim. Hence, in Malaysia the development of health and education become one of the major agenda of the government. The government should place a strong emphasis on health as a crucial factor. For society to receive treatment, the government must create better hospitals. However, the rising expense of hospitals, on the other hand, imposes a burden on society, particularly for the poor. Therefore, the Waqf An-Nur Corporation Berhad (WANCorp) constructed the first clinic to provide health services to the community in 2007. The first *waqf* clinic in Pasir Gudang was Klinik Wakaf An-Nur (KWAN), which eventually became Hospital Wakaf An-Nur (Mohamed & Rahman, 2015). WANCorp has opened 20 clinics, including hospitals, and has received 1,281,766 patients to date. The goal of this hospital is to provide medical treatment and health care at a cost that the general population, particularly the poor, can afford, regardless of race or religion (Mohd, 2015; Isa et al., 2011).

Since the establishment, KWAN has given services to patients in several states such as Selangor, Negeri Sembilan, Sarawak, Perak and Pulau Pinang. Treatment is provided to 135,095 non-Muslims and 1,146,675 Muslims. While 442 individuals were treated with dialysis on 66 dialysis machines as part of the cash *waqf* programme. An increase in the number of patients or beneficiaries has a beneficial impact on *waqf* institutions' performance efficiency as intermediaries. This is because the input has been fully utilized and produced the maximum number of outputs. Indeed, the importance of *waqf* as a means for assisting the poor and needy can be achieved.

Waqf also plays an important part in the development of religious schools. *Waqf* education institutions are organisations that have grown as a result of the use of *waqf*, whether in the form of money, land, or buildings, for the purpose of religious education. The first *Waqf*

school in Malaysia was 'Sekolah Pondok,' which led to the foundation of Madrasah, which was eventually turned to religious schools. In Malaysia, there are three types of waqf schools, each with a different ownership and management structure. The first form of religious school is recognised as a private school under waqf ownership, with the teacher or society in charge of management. This school, on the other hand, was funded by the federal or state governments, as well as the state Islamic Religious Council. State Religious Schools (SAN) and Society Religious Schools (SRS) are two other types of waqf schools (SAR). Both schools are managed by SIRCs as sole trustees and are completely funded by the state government.

Malaysia aspires to have a waqf-based institution or higher education, notwithstanding the expansion of waqf in other sectors. Thus, in line with the government's policy to transform higher education through "Pelan Strategik Pengajian Tinggi Negara," which emphasises self-employment for the purposes of development and management, waqf is seen as one of the solutions to the financial issues in education. Furthermore, rising development costs have a considerable impact on education costs. Indirectly, the poor Muslims are affected by the current scenario. Despite the fact that Malaysia does not yet have a waqf-based university, certain higher education institutions have begun to develop a waqf university or waqf-based university model that focuses on the collecting of cash waqf. As a result of this research, we have found six (6) state universities and one (1) private university in Malaysia that have developed a waqf endowment scheme.

Hence, undoubtedly the development of *waqf* assets gives a positive impact towards the development of nations and enhancing the economics of Muslims ummah. Many Muslims can receive the benefits from the development of *waqf* assets such as free medical treatment, reduced the unemployment rate, reduce government expenditure and enhance the education systems.

Cost of Rising Children with ASD

ASD is a relatively common incurable neurodevelopmental disorder that associated with the family financial burden. Early diagnosis is needed for the early execution of multidisciplinary treatment, which in turn improves the result. Children with ASD need a wide range of multi service provider, such as medical, behavioural, and other specialized therapies. The families usually spend a high amount per year and increase the out-of-pocket expenditure due to this illness. The larger financial burden is related to ASD parents or caregivers work loss. This is due to increased needs and other negative financial consequences for their ASD children (Togneri, 2014). Their parents have significantly higher financial burden than families whose children have other special health care needs.

Furthermore, rather than sending their children to a general hospital for once-a-month therapy, parents with ASD children should be given the option of sending their children to other private children's development centres that offer more cheap and frequent therapy sessions (Tipton & Blacher, 2013). Frequent and consistent therapy can help children proceed well and make it easier for the therapist to monitor their physical, mental, and emotional development in order to prepare them for school or college (Rose, 2014). It is also possible to improve the quality of life and well-being of children with ASD and their families by doing so. It is crucial to recognise that parenting a child with ASD comes with a slew of other

challenges, including the financial and time burden of medical care, limitations on social activities, and shifts in family objectives and achievements (Etournaud, 2017).

The total cost of raising a child with ASD is estimated to be approximately three times greater than the cost incurred by raising a typically developing child. Moreover, the financial costs of caring for a child with ASD can be associated with unpleasant effects in the lives of families of children with ASD (Järbrink et al., 2003). This has been supported by Fletcher, Markoulakis and Bryden (2012) explained that general expenses such as special dietary requirements, treatment costs, private lessons, childcare and cleaning/repairing homes were all mentioned as additional financial costs these families had to experience. The study by Järbrink et al (2003) also described the added financial burden of caring for children with ASD. Costs associated with out-of-pocket expenses and the use of formal and informal services were reported as contributing to the burden experienced.

Furthermore, Fletcher et al (2012) also stated the impact had on parents' employment and reported that parents had to take leave of work or give up their employment due to the extra responsibilities of caring (for example, additional medical appointments) for a child with ASD, whereas one of the mothers reported having to work full time to pay for the additional costs associated with her child's treatment. Fathers' employment was also reported to be affected, but not to a similar degree as mothers. Research by Järbrink et al. (2003) also mentioned that the alterations in employment resulting from the autism and mothers' jobs were more affected than fathers' employment.

Currently, there has been a steady increase in the number of children diagnosed as having an ASD. Report from the Centers for Disease Control and Prevention in 2006 indicated there is a growing number of ASD children in Malaysia that was 1 in 110 children. Surprisingly, the number had increased to an average annual rate of 57% between 2002 and 2006. Indirectly, the demand for services to meet the needs of these children and their families has increased (David, 2013). Despite the rise of ASD children year by year, the Malaysian government is now undertaking a number of measures to assist parents in obtaining and receiving early intervention for the children as well as other financial supports. Therefore, the government also starts to help the parents of children with ASD by providing them with financial support. However, the support is still not enough to provide service for the treatment, therapy, medicine, and others for children with ASD. Meanwhile, private special needs education is expensive and inclusive education where special needs children can learn together with neurotypical children is hard to come by. Parents of children with autism reported significantly less satisfaction with the assistance they have received since their child's diagnosis. About 93% of parents of children with ASD did not receive adequate financial support for their child's therapy (Etournaud, 2017).

Governmental Expenditure on Children with ASD

The government also starts to help the parents of children with ASD by providing them with financial support through monthly allowance. However, the allowance is still not enough to provide service for the treatment, therapy, medicine, and transportation for children with autism (Hisham et al., 2013). Meanwhile, private special needs education is expensive and inclusive education in which special needs children can learn together with neurotypical children, is scarce. Hence, Waqf initiatives would be another great alternative for the parents

to increase their financial condition, thus, enable them to send their children to the specific children development centres for early intervention. As a result, parents of children with ASD will no longer experience problems due to the high increase in household expenses.

In Malaysia, special education for children with ASD is expensive. However, despite the heavy financial incurred, budget that allocated by Malaysia governments still accessible in providing special schools and inclusive education for this populations. In fact, the Seventh Malaysia Plan impact on the establishment of 26 special schools for children with disabilities, including people with ASD. This inclusive education programmes saw the enrolment of children with disabilities along with normal children in 139 schools. It is observed that between 1996 to 2000, the special schools offered about 2,050 places to children with disabilities. Additionally, 6,890 places were extended to children with disabilities in inclusive education programmes in primary schools. Later, public policies in Malaysia endorsing the practice of special education in government special schools and inclusive education programmes also propagate research in special education to add value in transforming policies into effective education practice.

Besides education, ASD patients also supported by other incentives and subsidies. Government incentives and subsidies are referring to money paid by government to help individual, organization or industry to reduce its costs, so that it can provide products or services at lower prices. Currently, they have been provided with monthly allowances, therapist centres, medical aids educations and others. In the current global environment of unpredictable economic adversity, financial assistance appears to be more important in order for people to make it through hard times.

This huge number of expenditures had concerned the government and despite the huge amount used by government, parents and caregiver's are reported to still been burden by financial stress to proper raised children with ASD (Benevides et al., 2016; Chandran et al., 2019; Seymour et al., 2013). They usually have a variety of obligation expenditure to meet their unique needs (Dudley & Emery, 2014) and this obligation is continuously since there is no known cure for ASD. Many of them are looking for financial assistance, including government subsidies and incentives. However, children with ASD should be referred to the Department of Social Welfare. This will enable the child to be registered for benefits such as, placement to special needs education if warranted, welfare support including financial allowances from the department, free education and health services in the public sector and others. All of the benefits provided for the autism community is to ease the burden of low-income fairly to receive quality and standard care for their special child. Many low income and needy families received subsidies by the government either in monetary or non-monetary (Healy & Dunifon, 2014).

Conclusion

The diagnosis of ASD may also expose parents to stigma in the form of peer dismissal, stereotyping, and isolation, in addition to the financial pressure and time spent on special care needed. Such stigmas are additional obstacles for parents to raise children with ASD (Kinnear, Link, Ballan & Fischbach, 2016). The increasing number of ASD cases has contributed to higher healthcare costs for parents requiring consultation and treatment at different facilities. In order to meet the assessment and intervention needs of children with

ASD, both public and private autism centres have been set up. There is a major economic strain on families of children with ASD and it is not only limited to healthcare costs (Lavelle et al., 2014). In addition to prescription drug use, children with ASD need a greater number of visits to health care services and special educational services (Lavelle et al., 2014).

Financial well-being is important to protect parents and caregivers with ASD children. This responsibility of having children with ASD is risking their well-being and quality of life (Herrema et al., 2017) both positively and negatively (Ilias et al., 2017). In fact, having a child with ASD often leads them 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.

These concerns will make raising an ASD child extremely expensive. Caregivers and families of children with autism face a variety of unexpected and inescapable personal and financial costs associated with raising children with ASD. Loss of job and income due to the child's increased needs, as well as substantial out-of-pocket payments, are common household costs (Togneri, 2014). They should be given an alternative rather than sending their child to a general hospital, which is once-a-month therapy, to other private centres that offer more affordable fees and frequent therapy sessions (Tipton & Blacher, 2013).

Another perfect choice for parents of children with ASD to improve their financial condition will be the Waqf projects. It helps them to send their children to specific early intervention centres. It is a wonderful chance to help parents of children with ASD to improve their financial assistance if the waqf-based funding will thereby minimize the risk of not sending their children to get early intervention. Waqf thus plays an important role in raising the needs of children with ASD and their caregivers, in particular for lifelong learning. The role of waqf as an Islamic financial instrument can be seen to improve the well-being program in general and specifically to improve the quality of life of Muslims.

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