

THE EXPENDITURES OF AUTISM CAREGIVERS: EXPLORING THE POTENTIAL OF WAQF AS FINANCING CAPITAL

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Abstract - The development process of children with autism spectrum disorder (ASD) included physically, emotionally, socially, intellectually, and others. Unfortunately, the ASD available symptoms have been shown to significantly affect negatively such a low negative well-being (Gardiner & Iarocci, 2012; Ilias, Liaw, Cornish, Park, & Golden, 2017) and lead to stress among caregivers especially family as the main starter for ASD development. This study focuses on autism caregivers which is one of the mental health prevalence that commonly affecting youth beside bipolar disorder, conduct disorder, attention deficit/hyperactivity disorders, learning disorders, eating disorders, and childhood onset schizophrenia (Kamarulzaman & Jodi 2018). The rising of this ASD prevalence has raised concerns about the burden on government subsidies and government, caregivers still been burdened by financial stress to proper raised children with ASD. Beside financial, the psychological stress also burdens autism caregivers. According to Picardi et al., (2018), for caregivers, having a child with ASD are multifaceted and pervasive. This study aimed at exploring the subjective and objective burden of autism caregivers, and at the same time, improving the understanding about their internal burden, child's characteristics, and parents' coping resources and strategies. In fact, government or policy maker should move towards setting up alternative in a planned manner in ensuring that the alternative selected are in place. The general finding of this paper will show that, there should be strong willingness from government to devote, and make waqf institution as one of the financing capitals for ASD prevalence. Waqf as a financing instrument plays a huge role in upgrading the capabilities of the needy, especially to children with ASD and their caregivers. The function of waqf as Islamic financial instrument is proven in enhancing well-being in general and specifically for improving the quality of life of Muslim. Hence, this institution surely can assist the issue as alternative resources for government's ASD expenditure.

Keywords: Autism Spectrum Disorders; Caregivers; Expenditures; Waqf; Well-Being

INTRODUCTION

Public health has concern people around the world. One of the critical parts in public health is mental health (Malaysian Healthcare Performance Unit, 2017). In Malaysia, according to Malaysian Health Minister Dr. Dzulkefly Ahmad, around 4 million people who are suffering from mental health issues (Carvalho, Sivanandam & Shagar, 2018). Adolescence commonly, affected by anxiety disorders and depression disorders, distinguished by hopelessness or helplessness state that is disruptive their daily life. This study focuses on ASD which is one of the mental health prevalence that commonly affecting youth, besides bipolar disorder, conduct disorder, hyperactivity disorder, learning disorders, eating disorders, and childhood onset schizophrenia (Kamarulzaman & Jodi 2018).

Usually, children with ASD face a complicated social, emotional, and behavioural difficulties (Hastings 2003; Lecavalier et al. 2006; Tomanik et al. 2004; Seymour, Wood, Giallo, & Jellet, 2013), but the numbers of person with ASD affected by psychological issues might be higher in adults, as social anxiety and depression often emerge during adolescence. According to Roux and Kerns (2016), these circumstances are more common in adolescents with autism than in those with other types of



disabilities. Concurrently, there was a raising number of ASD prevalence. Report from the Centres for Disease Control and Prevention (CDC) in 2006 indicated that the prevalence of ASD was 1 in 110 children. Surprisingly, the number had increased to an average annual rate of 57% between 2002 and 2006. Despite on the rising of autism prevalence, financial burden issues have raised concerns on the government subsidies and expenditure.

Analysis on the government expenditure on autism well-being showed that the number has been increasing year by year. Despite the huge amount used by the government, caregivers are still been burden by financial stress to proper raised children with ASD. Statistically, 75% of children with ASD need occupational, physical, or speech therapy services. Some of them do not achieve or fulfilled any therapy needs. In addition, the percentage that does not fulfilled therapy need in 2009 until 2010 is higher than in 2005 until 2006. This is due to the limited access for funding (Benevides, Carretta, & Lane, 2016).

Study by Wang and Leslie (2010) had found that the total expenditure to raised children with ASD prevalence was high and keep rising over time. This statement had been supported by Landon, Shepherd, and Goedeke (2018) which also stated that the impact on caregivers' financial stress strongly related to reduce of their life satisfaction. Besides, they also are often facing other mental health difficulties, including depression and anxiety (Seymour et al., 2013). Besides that, Willet, Dorstyn, Due, and Li (2018) indicated that fund is a critical factor for caregivers who are financially disadvantaged.

A good resourcing and funding can enhance the availability for children with ASD to access good support service which in turn, can promote well-being for both caregivers and children. Thus, this paper proposed a model adapted by previous research that are well suited for alternative resources for autism caregivers in Malaysia. The model also intended to develop further understanding on the usage of waqf as an alternative financing capital or pathway to reduce parenting financial stress and burden by government to maintain subsidies for children with ASD.

This research is significant for government or policy maker to changeover or setting up an alternative funding with waqf. Waqf as a financing instrument has a huge effect to upgrade the capabilities of the needy and enhance their quality of life by providing access to autism healthcare funding and facilities. The function of waqf is proven as relevance instrument in promoting well-being in general and specifically for improving the quality of life of Muslim.

In context of Malaysia, there is still lacking in executing the waqf as the main contributor to support autism well-being. Therefore, general finding of this paper shows that there must be strong willingness and commitment from government to devote and benchmarking good practices of waqf/endowment institution as one of the financing capitals for expenditure especially for children with ASD.

LITERATURE REVIEW

1. Care and Wel-Being of Children with ASD and Caregivers

Autism society of America has defined ASD as the complex's development disability that usually appears during early childhood and can affect person's ability to communicate and interact with others. However, WHO referring ASD as *"a range of conditions characterised 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 tend to remain the whole life. However, in certain cases, this disorder only appears in the period of the first five (5) years of life. This organisation stated that people with disorder usually born with similar condition such as epilepsy, depression, anxiety, and attention deficit hyperactivity disorder (ADHD). Meanwhile, their level of intelligent is tremendously inconstant, which is in the range of low to extremely high levels.

ASD also refer as a spectrum condition that effect individual differently to varying degree (refer table 1). According to table 1, 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). As one



of the mental health prevalence that commonly affecting youth, ASD likewise has been the limelight in Malaysia (Kamarulzaman & Jodi, 2018).

SEVERITY LEVEL	SOCIAL COMMUNICATION	RESTRICTED, REPETITIVE BEHAVIOURS
Level 3 "Requiring very substantial support"	Severe deficits in social communication skills, very limited initiation of social interactions & minimal response to social overtures from others.	Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/ repetitive behaviours markedly interfere with functioning in all spheres. Great distress/ difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in social communication skills, limited initiation of social interactions & reduced or abnormal responses to social overtures from others.	Obvious interference with functioning in a variety of contexts. Distress &/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions & a typical responses to social overtures of others.	Inflexibility of behaviour causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization & planning hamper independence.

Although there are none official statistic of total registered individuals with autism diagnosed within all 3-severity levels in Malaysia (See, 2002), the World Health Organisation, estimated that 1 in 160 children on this earth has this prevalence. Anyhow, in 2013, 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. The increase of 45.3% cases within a year prove that there is a drastic increase of ASD in Malaysia (Murad, 2019: National Autism Society of Malaysia (NASOM) Chairman, Feilina S.Y. Muhammad Feisol, 2019).

Nowadays, in accordance with the advance ASD study globally, the increase in new finding to ASD development program had been established. Although there is no known cure for ASD, most research profound that an early intervention such as behavioural treatments and skills training programs during their childhood will enable them to reach the optimal development and well-being. Thus, it is recommended for caregivers of children with autism to monitor their child development in the early life stage to avoid error in communication and social behaviour.

According to Dillenburger, Jordan, McKerr, and Keenan (2015), early diagnosis of a child with autism will bring different life to the child with ASD and their family. Yet, the major consequences of ASD to people with this prevalence and their families are emotional disruption and economic burden whereby the more severe form of ASD level (refer table 1), the more demanding the sacrifice required. However, in clinical aspect, most care systems are organised to meet the needs of individual with ASD not the family caregiver (Karst & Van Hecke, 2012). Although the emerging public health concern with multifaceted psychological, social, and economic implication. This negative impact of bad well-being will lead into high levels of mental and physical health problem, social isolation, and financial burden.

Family is a basis society functioned as an institution that can resolve and ease social problem. Family traditionally consists of two parents rearing their children or several of social units differing from but regarded as equivalent to traditional family. One of the challenges for parents to become the leader of one family is difficulties to deal with their child's behaviour and emotional problem. In fact, most of the children development learning process starts with family since they are born.

The development included physically, emotionally, socially, intellectually, and others. The critical condition occurs when the children is 'different' in many aspects and requires specific requirement



(Dillenburger et al., 2015). In the prospect of ASD development process, family members are the first and primary caregiver for them. Not just autistic child, for autistic adult, external support often diminishes and family members frequently become the primary source of support.

This responsibility is risking their well-being and quality of life (Gardiner & Iarocci, 2012; Ilias et al., 2017) both positively and negatively (Cridland, Jones, Magee, & Caputi, 2014; Ilias et al., 2017). The more severe the ASD child is, the more related to decreasing of parents' well-being. They always endanger by falling of mental health, higher level of worry, depression, anxiety, and stress (Herrema et al., 2017).

According to McConkey and Samadi (2013), compared to mothers, fathers were shown to consistently reported lower scores of psychological impacts of having a child with ASD and higher ratings of physical health. Study by Hodgetts et al. (2013a) had interviewed parents of nine males with ASD and aggressive behaviour, ranging from age 6 to 29 years. Themes emerged surrounding the negative impact the children's aggressive behaviours had on their parents' sense of well-being.

While well-being was not explicitly defined, caregivers spoke their feelings of isolation, exhaustion, safety concerns, and financial consequences associated with their children's aggressive behaviour. On the other hand, other researches had found that fathers' ratings of well-being do not appear related to child behaviour problems (Allik et al., 2006; Hastings et al., 2005b; Jones et al., 2013). Besides, mothers of children with ASD always related to unemployment among family. The unemployment will lead to financial hardship and poverty, especially to single mothers. The reason for the unemployment is due to looking after the child with ASD (Dillenburger et al., 2015).

In the meantime, an interview conducted by Ilias et al. (2017) to six (6) caregivers of children with ASD (Malaysia mothers from different ethnic backgrounds) directly mentioned the significant of financial problems due to the costs of private therapies. The participants did not deny the importance of money as the main issue in bringing up a child with ASD. According to one of the participants, most of the saving only used for the autistic child until they could not afford the additional cost for education with applied behaviour analysis therapy.

The worse cases are when the family is residing in rural area. They faced more challenges in finding resources. Although government providing a lot of therapies in rural or city in government hospitals or clinics, there is a need to face a long waiting list. This circumstance obliging the family to switch treatments in the private sector or turn to alternative treatments.


In the current global environment of unpredictable economic adversity, financial help appears to be more important for people to make it through hard times. People with ASD and their family often have variety obligation expenditure to meet their unique need (Dudley & Emery, 2014). Many of them are looking for financial assistant, included by government subsidies and incentives.

Government incentive subsidies referring to money paid by a government to help an organisation or industry reduce its costs, so that it can provide products or services at lower prices. For Malaysian ASD prevalence, currently, they had been provided with monthly allowances, therapist centres, medical aids, educations, and others.

2. Government Expenditures for Children with Autism

The concept of well-being had been introduced by World Health Organisation (WHO) in 1948 (Jakab, 2011). Well-being is defined as "a state of mental, physical and social well-being." Throughout the years, well-being concept has sustained its place as the main agendas for many governments and policymakers around the world. Meanwhile, for individual well-being had recently consideration to become indicators of family well-being. Many governments had taken interest in family well-being due to increasing policy about interest in children's welfare, and recognition of the role of families in nurturing children's well-being (Wollny, Apps & Henricson, 2010).

People with ASD and their family often have variety obligation expenditure to meet their unique need (Dudley & Emery, 2014). Many of them are looking for financial assistant, included by government. Government existence and involvement in helping people with ASD had been recognised from back then until now. This organisation plays a major role as significant assistant to ASD and other people with disability in providing accessible benefits. In 2017, numbers of people with disabilities



registered with Department of Social Welfare Malaysia (which is one of the government agencies) is almost 419,805. Registered people with ASD are almost 3.6% from the total registered, which up to around 15,484 people. Selangor has the largest number of registered children with ASD in Malaysia, which is 3,345. Meanwhile, Labuan is the lowest (Department of Welfare Malaysia, 2018: Department of Statistics Malaysia, 2016).

For the development of children with ASD, in the same year, government had invested on Community-based Rehabilitation Centre (CBR) in all around 14 states in Malaysia. Currently, there are 537 CBR operate with almost 21,000 people with disabilities (mostly child). In 2013, the announced budget on child stated that government has agreed to implement childcare centre (CCC) for children with autism and children with other disabilities, such as down syndrome, blind sight, hearing loss, physical and learning disabilities. Unfortunately, although government had established CCC exclusively for autism prevalence, the centre is only located in Sibul, Sarawak. Meanwhile, children with autism in other states need to mix with another children with disabilities in one centre. The fact is, private autism care centre is quite expensive and majority parents of children with ASD cannot afford (Department of Welfare Malaysia, 2018).

Besides children, government gives full support to autism adults with training, rehabilitation, group home, job coach, training for independent living, institutional, protection, counselling, one stop centre, launching grant, financial assistant through allowance, working allowance and others. From the registration of People with Disability (PWD), children with ASD get a lot of benefit in employment, general assistant, discount, consultant, public transport benefit, easy access of public facility and others. The facility provided for children with ASD also include financial scheme to ensure they can participate in the mainstream society (Landon et al., 2018). Autism worker allowance is provided for them with monthly income less than RM1,200.00. Those who are unable to work will receive an allowance of RM200.00 per month (with doctor certified). Lastly, RM2,700.00 is a maximum amount provided by the special grant, to help ASD to start a small business (Department of Social Welfare Malaysia, 2017).

Despite that, the article 27 of The UN Convention on the Rights of Persons with Disabilities (CRPD) provides a legally binding global framework for promoting the rights of people with disabilities (including psychosocial disabilities). It recognises that every person with a disability has the right to work, should be treated equally and not be discriminated against, and should be provided with support in the workplace (Tan Sri Lee Lam Thye, 2019). In the announced 2020 budget, government recently has agreed to distribute RM300.00 per person (*bantuan sara hidup*) with automatically free my *salam takaful* scheme, which is RM180.00 higher than the amount received in 2019. Autism with RM2,000.00 salary will be entitled to receive this payment. Furthermore, 50 million had been allocated to upgrade and maintain 67 institutions under JKM CCC. 20 million allocations for new independent learning centre with specialty to extended from the service tax. This is in line with zero project policy introduced by Ministry of Education that stated no disabled child shall be denied an education to her or his disability.

3. Autism Care Subsidies, Waqf Financing Capital, and Family Well-Being

All the benefits provided for autisms community is to ease the burden of low-income fairly to receive quality and standard care for their special child. Many of low-income and needy family received subsidies by government either in the shape of monetary or non-monetary such as help, education, therapist, medical aid etc. (Healy & Dunifon, 2014). This huge number of expenditures had concerned the government and despite the huge amount used by government, caregivers still burden by financial stress to properly raised the children with ASD (Benevides et al., 2016; Chandran, Jayanthi, Prabavathy, Renuka, & Bhargavan, 2019, Seymour et al., 2013).

For most people with ASD prevalence, caregivers play an important role when it comes to their complicated life process. Once the child with ASD is born or diagnosed, they require special needs such as physical, emotional, behavioural, or learning disabilities; and the caregivers need to face the unexpected spending. Thus, there are so many social and financial support services established using philanthropy for autism well-being in this world today such as National Autism Society of Malaysia



(NASOM) one stop centre in Malaysia, UW Autism Centre University of Washington, National Autism Society in United Kingdom, Scottish Autism FIFE one stop shops in Scotland and lastly, Alma Jordan riddle foundation. All these foundations established using endowment and philanthropy funding capital. However, the usage of waqf for autism care centre is far from exist.

Waqf is a religious charitable endowment under Islamic law. This endowment has contributed to the strengthening of the Islamic practices within the Muslim communities which typically involves donating a building, plot of land or other assets for Muslim religious or charitable purposes. Normally, waqf assets are utilised for both economic and social purposes, in which one of the popular uses of waqf is for funding the healthcare centre. For example, Faith Hospital in Istanbul, 50 hospitals in Egypt, Waqf An-Nur hospital and clinic in Johor Malaysia, Myint Myat Phu Zin clinic model in Myanmar and USIM health specialist clinic in Negeri Sembilan, Malaysia.

Waqf is one of the most important socio-economic institutions in Islam that falls under the category of sadaqah. A study conducted by Adewale et al. (2016) found that the development plan on waqf assets was somewhat hindered or delayed in almost all Malaysian states due to insufficient fund issues faced by most of the State Islamic Religious Councils (SIRCs) and the Department of Waqf, Zakah and Hajj (JAWHAR).

The role of waqf in developing the socio-economic sector has reduced significantly. This is because majority of the public thought that waqf is solely meant for religious purposes such as for mosques, surau and religious schools (Adewale et. al, 2016). However, waqf can bring benefits to all society especially for special needs children. The development of waqf in all over the world has proven that proper waqf can play significant roles in shaping the healthcare or charity development capabilities, particularly among children with autism.

The waqf assets are trusts that have potential to provide wealth and profitability to public (Hassan, 2010). Waqf has two (2) categories which are religious waqf and philanthropy waqf. Religious waqf is referring to revenues restricted by the mosque or real estate and will be spent on mosque's maintenance and running expenses to satisfy the religious needs. However, the philanthropic waqf aims to support the public needs (Kahf, 2003). Due to low understanding of waqf development, waqf is often viewed as just an act of devotion to God. Consequently, the authority of the legislation has allowed the administrators of waqf to add value to the waqf asset through the commercialisation or charitable activity.

Figure 1 is referring to the autism care subsidies provided by government expenditure, waqf financing capital and family well-being adapted from research by Healy & Dunifon (2014). The figure had suggested waqf as an alternative financing to reduce burden to maintain government subsidy to caregivers of children with ASD. Thus, the potential of waqf to be developed innovatively as the community well-being programs is undeniable.

Therefore, the aim of this paper is to propose the roles of waqf as financing capital in improving well-being of caregivers and children with autism. This paper explained the cases and possible solution for financial among caregivers of children with ASD by reviews how waqf can be structured to perform the designated role.

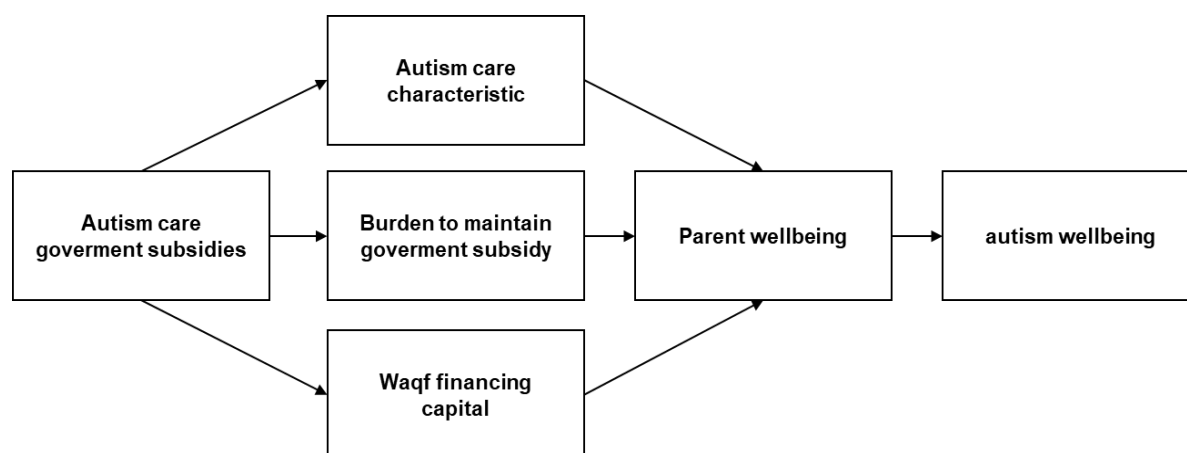


Figure 1: Autism Care Subsidies, Waqf Financing Capital and Family Well-Being

Source: Healy & Dunifon, (2014)

CONCLUSION

ASD has increased in recent years. Having a child with ASD often leads caregivers to a path that is riddled with frustration, difficult decisions, interfaces with various professionals and specialists, and endless research for better understanding and alternatives. 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, they require more attention and consistent early intervention, and all of these will cost money. Therefore, it is very important to ensure the public are aware about the autism care and well-being to indicate their emotional and mental support to caregivers of children with autism.

The caregivers 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 centre. This is because this kind of centre incurred high fees according to the level of autism of the children as well as depending on the frequency of therapy needed.

Children with autism should be well-trained since young to ensure they are capable in managing their daily routine as well as expressing their feelings effectively. Other than that, a lot of knowledge and sharing session will be given to the caregivers when they actively send their children to the early intervention centre.

ASD care subsidies affect a vast majority of low-income families, and a small but growing body of literature examines the influence of government subsidies on measures of family well-being. Waqf funding capital is believe as a mechanism to lessen the government spending for specific purposes and cover ASD expenses entirely such as ASD one stop centre operational costs, medical aids, therapists, including allowances for students with ASD.

Collaboration between government and waqf institution should make a significant contribution in managing the expenditures for children with ASD. Therefore, the government expenditures in ASD would reduce significantly by waqf. This study aims to investigate the relationship between ASD care subsidies and parents and children's well-being, and the impact of waqf financing capital as moderating variable between government subsidiaries and caregivers and autism children's well-being.

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