

# Well-Being of Caregivers of Children with Disabilities: Role of Islamic Philanthropy

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## Abstract

**Purpose:** The primary aim of this study is to identify the factors that influence the well-being of caregivers of children with disabilities. In addition, to determine how Islamic philanthropy would be able to address this issue. Specifically, this study will identify the role of zakat and waqf in enhancing the well-being of caregivers of children with disabilities.

**Design/methodology/approach:** This paper involves secondary and primary data sources which are text studies and field studies on certain respondents such as parents/guardians of children with disabilities, related parties with legislation, the party that manages waqf property (Mutawalli) and zakat (MAIN), and the party that provides therapy facilities and Community Rehabilitation Centres (PPDK) by the Department of Welfare and Society (JKM).

**Findings:** This study is anticipated to create possibilities for treatment and therapy for caregivers of children with disabilities, thereby fostering a beneficial influence on their child's developmental and potential.

**Research limitations/implications:** Islamic philanthropy has the potential to contribute to the growth of the national economy by alleviating the financial strain on many sectors, including educational institutions, hospitals, and community infrastructure requirements.

**Practical implications:** Islamic philanthropy, particularly through the mechanisms of zakat and waqf, significantly contributes to the improvement of the welfare of caregivers of children with disabilities.

**Originality/value:** Zakat and waqf institutions have the opportunity to develop suitable measures to ensure that caregivers are equipped to effectively care children with disabilities, with the ultimate goal of encouraging their independence as they grow up.

**Keywords:** Caregivers, Children with Disabilities, Islamic Philanthropy, Parents, Well-Being

## Introduction

Around 15% of people worldwide have some types of disabilities, and of those, 2 - 4% struggle with significant difficulties in functioning (WHO, 2011). According to the Department of Social Welfare, which manages the Persons with Disabilities (OKU) registry, there are a total of 637,537 persons with disabilities as of 31 January 2023, which is about 1.9% of the Malaysian population. Caregivers, particularly those caring for individuals with disabilities, often report high levels of stress (Schulz & Sherwood, 2009; Biegel et al., 1991). The stress can result from the demands of caregiving, financial pressures, and the emotional toll of seeing a loved one struggle with a disability. The task of raising children with disabilities is already challenging, as it encompasses various physical, psychological, and mental effects (Ilias et al., 2019). Hence, caregivers of children with disabilities who encounter low psychological well-being

inadvertently exhibit unfavourable parenting skills or conduct, thereby impeding the ability to optimise the developmental capabilities of children with disabilities.

In a health perspective, caregivers' health can be negatively affected by the stress of caregiving. This stress can lead to physical health problems, such as sleep disturbances, depression, anxiety, and even chronic illnesses. Moreover, caregivers feel isolated and unsupported in their roles. They may lack access to respite care, counselling services, and other resources that could help alleviate their stress. Caregiving can affect a caregiver's overall quality of life, leading to reduced social engagement, leisure time, and personal fulfilment. In addition to that, providing care for someone with a disability can be costly. Caregivers of children with disabilities may face financial difficulties due to medical bills, home modifications, and reduced income if they need to reduce their work hours or quit their jobs to provide full-time care for their children with disabilities (Cooke et al., 2020).

The financial difficulties can significantly burden caregivers of children with disabilities due to the extra costs associated with providing care and the potential loss or reduction of income. The children with disabilities may require frequent medical appointments, therapies, and treatments (Jani et al., 2022). These medical expenses can be a significant financial burden, especially if they are not fully covered by health insurance or government assistance programs. However, inadequate financial support such as government assistance and insurance may not fully cover the costs associated with caring for children with disabilities leads to another challenge (Ilias et al., 2019). Therefore, there is a need to explore beyond government support in facilitating the financial burden among caregivers of children with disabilities. Of all, Islamic philanthropy may play a significant role in addressing the financial challenges faced by caregivers of children with disabilities (Jani et al., 2023). For instance, the role of zakat, and waqf funds should be explored to ensure the funds can be allocated to support caregivers of children with disabilities.

Islamic philanthropy, rooted in Islamic principles and values, emphasizes helping those in need, promoting social justice, and improving the well-being of the community. Islamic philanthropy has the potential to mobilize substantial resources and channel them effectively to support caregivers of children with disabilities. By aligning philanthropic activities with Islamic teachings and values, the community can contribute to addressing the financial burdens caregivers faced, promoting inclusivity, and enhancing the overall well-being of families caring for disabled loved ones.

Caregivers need to navigate complex systems and obtain the financial support they need, leaving them to cover a significant portion of the costs themselves. The financial difficulties associated with caregiving for a child with disabilities can be extensive and have a lasting impact on a caregiver's financial stability, career, and overall quality of life (Cooke et al., 2020). It is important to identify the factors that influences the well-being of caregivers of children with disabilities to ensure adequate support and resources. This is done with the aim of assisting caregivers in efficiently navigating the financial hurdles associated with their caregiving responsibilities. Thus, the objective of this study is to identify how Islamic philanthropy can be empowered to address this issue. Specifically, to explore the role of zakat and waqf in enhancing the well-being of caregivers of children with disabilities.

## **Literature Review**

### ***Challenges Faced by Caregivers of Children with Disabilities***

The role and responsibilities of providing care for children with disabilities presents a substantial difficulty for both the children and their caregivers. Caregivers might encounter substantial financial difficulties, such as high healthcare costs that are not covered by insurance, as well as unemployment (Akram et al., 2019). A number of scholarly researches have extensively documented a diverse range of psychosocial difficulties that affect individuals who provide care for children with disabilities.

In addition to this, caregivers of children with disabilities have a diverse array of challenges pertaining to their relationships with other people, occupational status, financial security, and notably, the lack of available resources and efficient management procedures (Muhammad et al., 2019). Considering that caregivers often serve as the very first point of interaction for young children, it is important to prioritize an in-depth understanding of their well-being. Therefore, it is crucial to examine the challenges encountered by caregivers of children with disabilities in order to enhance the administration of healthcare services and provide adequate financial assistance.

A study conducted by Ariffin and Abdullah (2020) identifies several issues that contribute to the limitation of support and assistance for individuals with disabilities. The financial difficulties create an important challenge for the majority of countries. The allocation of financial resources for welfare programmes and services is significantly constrained, particularly in economically disadvantaged countries (Ilias et al., 2019). Moreover, the inadequate availability of human resources, particularly caregivers or house assistants, hinders the effective implementation of the community-based service system (Cooke et al., 2020).

This phenomenon is especially common in rural areas, where there is a significant trend of young individuals migrating from their home towns. In a study conducted by Ariffin and Abdullah (2020) they stated that in major urban centres, the phenomenon of transmigration generally involves an immigration of caregivers coming from less economically advanced countries, such Indonesia, Philippines, and Cambodia. These individuals willingly undertake caregiving roles within families residing in developed urban areas.

Other than that, the services provided for individuals with disabilities within institutional settings are often well-received due to their potential to alleviate the responsibilities faced by family members (Ariffin & Abdullah, 2020). However, it is important to acknowledge that these services may not fully cater to the diverse requirements of all individuals with disabilities (Muhammad et al, 2019; Rosli et al., 2020). Hence, it is important to strengthen the views pertaining to caregiving within family and community contexts in order to foster self-assurance and enable individuals with disabilities.

The responsibility of providing care for a child with disabilities poses a substantial hardship to caregivers. They find it difficult to get relevant information from family members, relatives, or friends whereby this situation creates a challenge for them (Muhammad et al., 2019). Other than that, this leads to an increase in the level of pressure experienced. The presence of supportive family members and effective collaboration between parents/caregivers and medical or hospital staff members, such as medical social workers, may potentially reduce the experience of stress (Rosli et al., 2020).

In the present-day context, a growing number of caregivers have developed an understanding of the significance of reporting their children or other family members who fall under the

category of person with disabilities (PWDs). By implementing this approach, the family has the opportunity to obtain a monthly financial support (RM300.00) for each family member who falls within the classification of being disabled (Department of Social Welfare Malaysia, 2019). Despite the insufficiency of the financial contribution to cover expenses related to food and drink, medical treatment, and other necessities for PWDs, the availability of financial support remains beneficial, particularly in cases where mothers are unable to engage in employment due to their caregiving responsibilities towards their children with disabilities (Akram et al., 2019).

One crucial aspect pertaining to the providing care for children with disabilities is the cultivation of awareness among family members. This is due to the fact that if family members, particularly caregivers, fail to officially register their children as disabled, they would be unable to access the services and resources designated for those with disabilities (Ariffin & Abdullah, 2020). The failure to register, whether due to lack of awareness, intentional avoidance, or lack of knowledge on the disability status of child, can be regarded as a manifestation of neglect and discrimination (Moore & Bedford, 2017).

In order to minimise the continuing existence of this issue, it is crucial to prioritise endeavours aimed at promoting parental registration and fostering an understanding of their obligations pertaining to the well-being and advancement of PWDs. In the realm of caregiving, it is essential for families and communities to collaborate in order to provide assistance for the empowerment of children with disabilities and their respective families (Ilias et al., 2019; Ariffin & Abdullah, 2020).

### ***Islamic Philanthropy***

Islamic philanthropy is a practice of voluntary donation, provision voluntary services and bodies/institutions that provide donations or services voluntarily (Faozan, 2017). Western scholars believe that philanthropy is a practice voluntary whether through individuals, associations or non-governmental organizations that are implemented for the sake of general good that focuses on improving the quality and well-being of life (Mustafar et al., 2022). Conceptually there are several instruments of Islamic philanthropy that exist such as zakat, waqf, and sadaqah.

Zakat comes from the word zaka which means good, blessing, pure, grow and develop (Budiman, 2018). According to the term, zakat is a certain amount of property that has met the conditions certain that is required by God to be released and given to those who are entitled to receive it with certain conditions. Zakat is also an important component of the economy especially for the socioeconomic system of Muslims in Malaysia in addition to the existing tax system (Nasir et al., 2021).

Zakat serves as the foundation for the social protection measures that are provided by Islam. (Sutrisno, 2017). Payment obligations, specific, and extensive expenditures, and the role of government in zakat management shows that it is a unique social protection. Zakat is an institution which plays an important role in ensuring social justice in society, and helping people in achieving their main goal created by Allah S.W.T (Wahid et al., 2012). Therefore, zakat is the best solution to take care of the economic benefits of Muslims because it has been enshrined in the five pillars of Islam that must be believed and obeyed.

The next form of Islamic philanthropy is waqf. Waqf means to stop, save, or maintain. In Islamic terms, waqf refers to the voluntary donation of one's wealth and irrevocable which is in the form of land, house or garden, cash, and its use for sharia-compliant projects such as mosques or religious schools. Waqf only allows property that is not destroyed or destroyed because the benefits from the property must remain until the end. Waqf also provides something that benefits many people and not intended for certain people only.

Waqf has the potential to reduce social gaps, and can improve the quality of life. In addition, waqf also plays a role in health services, poverty eradication, education, and others (Ismail et al., 2019). It is clear that waqf has contributed to development and the strengthening of the Islamic community in terms of economy, social and education. Usually, waqf assets used for social and economic purposes, in fact one of the popular benefits of waqf is funding centres that offer health services. Waqf proceeds can be used to provide health and education facilities, clean water, facilities that can be used by the public, improve economic well-being, and reduce the economic gap.

In relation to the practice of waqf in ensuring well-being among caregivers of children with autism, waqf has various methods to achieve this goal. Endowment of assets such as buildings or land acquired from individuals who give waqf can be used as facilities for the purpose of therapy and education for children with disabilities (Jani et al., 2021). Therefore, the operator of this centre can use the facility for free and no rental fee is charged to the entrepreneur. Indirectly, employers can reduce charges to the caregivers as well as reduce the expenses imposed by the entrepreneur to obtain the necessary services.

It can be done at once help ease the financial burden of parents/guardians in ensuring autistic people receive treatment/therapy consistently as long as it is needed. Overall, the flourishing waqf institution in the Islamic world has ensured his people get perfect protection, nutritious food, quality education, and free health facilities (Suhaimi, 2022). This is a basic requirement human development. Without this opportunity and choice, other opportunities and choices will not be obtained which results in poverty will continue to impoverish, and become a cancer that is difficult to cure.

Ismail et al. (2019), stated that the best sadaqah is taken from the excess of the need and responsibility, and it is a sin if a person gives alms by reducing the alimony his responsibility. Sadaqah with sincerity and happiness because you will get a reward which is a lot and it is an act of worship. According to Noorfazreen et al. (2017), this sadaqah can become a symbol of unity and bond of heart between various layers of society. In addition, nature Philanthropy can be fostered among the wealthy through the implementation of responsibility set. This practice needs to be applied in individuals in the early stages in order to be able to give birth a generation that is philanthropic and likes to help the needy.

Sadaqah is very necessary to help the needy, especially the children with disabilities who need support throughout their lives (Jani et al., 2023) especially during the era where funding or government assistance is very limited. Along with the national goal to improve well-being people's lives, then it is important to focus on development and expand the role charity or Islamic philanthropy to fulfil the benefits of autistic people.

***Role of Islamic Philanthropy in Enhancing the Well-Being of Caregivers of Children with Disabilities***



Caregivers of children with disabilities often face frustration, difficult decisions, discussions with professionals and specialists, and endless research to better understand and find alternatives (Salomone et al., 2018). The idea that having a child with disabilities will be financially burdensome contributes to the stress. Caregivers of children with disabilities and their families face many unexpected and unavoidable personal and financial difficulties (Muhammad et al., 2019). This situation includes loss of job and income to meet the children's demands and substantial out-of-pocket expenses that are common household costs.

The government of Malaysia provided subsidies, in the form of either monetary or non-monetary assistance, to several low-income and economically disadvantaged families (Chandran et al., 2019). Despite the substantial resources allocated by governmental entities, parents and caregivers continue to experience financial strain in their efforts to adequately support children with disabilities (Jani et al., 2022). According to Dudley and Emery (2014), individuals with disabilities typically face a diverse range of financial obligations in order to address their specific needs. It is important to note that these obligations persist throughout time. The use of Islamic philanthropy funds has played an important part in delivering crucial financial aid to caregivers of children with disabilities (Jani et al., 2022). This support has effectively enabled these families to fulfil their fundamental requirements, hence averting the necessity for them to resort to unfavourable coping strategies.

Moreover, Islamic philanthropy especially waqf is widely recognised as a viable financial system that encompasses not only religious expenditures but also provides support for various global needs, including education, healthcare, social welfare, commercial ventures, and fundamental infrastructural development (Salleh et al., 2023). This Islamic financial tool has the ability to expand prospects for financing various sectors specifically in assisting caregivers of children with disabilities. Based on previous research, philanthropy such as waqf is inclusive for all, whereas waqf contributions for the disabled are more focused on health-related facilities. This is due to the fact that one of the most essential considerations when it comes to children with disabilities is their health (Suhaimi, 2022). According to Amin et al. (2016), financial and geographical constraints have prevented disabled people with symptoms of illness or injury from receiving early medical treatment, causing them to become permanently disabled. In order to obtain access to formal education, they had to overcome environmental barriers after becoming physically disabled.

A considerable number of caregivers of children with disabilities are actively seeking financial aid especially from government subsidies and incentives. However, before they can receive the financial assistance, it is important to register the children with disabilities to the Department of Social Welfare Malaysia. This will facilitate the child's enrolment in various benefits that include access to specialised schooling if deemed necessary, welfare assistance including financial allowances, complimentary education, and healthcare services in the public sector, among other entitlements.

The role of Islamic philanthropy in the field of social welfare is crucial in supporting the socioeconomic development of society in general and the caregivers of children with disabilities in particular (Jani et al., 2023). In Malaysia, the contribution of Islamic philanthropy can be seen in the establishment of various facilities and support for the implementation of various facilities and community requirements. Specifically for children with disabilities, philanthropic contributions can be divided into categories such as education, health, and economic development. The primary objective of the benefits offered to the children with disabilities is to alleviate the financial strain experienced by caregivers, so

enabling them to access high-quality and standardised care for their children with disabilities. In addition to that, Islamic philanthropy such as zakat funds can be allocated to support caregivers of children with disabilities as zakat is a mandatory form of charity in Islam and can be directed towards those in need.

Besides, sadaqah is another source from individuals, families, and communities which can be allocated to support the caregivers of children with disabilities. Sadaqah can help provide financial relief, respite care, medical equipment, and other necessary resources for caregivers. Likewise, another Islamic philanthropy that can be resorted to enhancing the well-being of caregivers of children with disabilities is waqf. The establishment of waqf funds dedicated to supporting caregivers of children with disabilities should be promoted. Income generated from waqf properties or investments can be utilised to provide financial assistance, healthcare support, and other needed services to caregivers of children with disabilities.

To be specific, the establishment and funding of Islamic philanthropic organizations focusing on caregiving can be developed. These organizations can mobilise resources, provide financial aid, offer education and training, and create a support network for caregivers of children with disabilities. To strengthen the funding, there is a crucial need to foster the collaborations and partnerships between Islamic philanthropic organizations, religious institutions, and community centres to pool resources and coordinate efforts to support caregivers of children with disabilities effectively. Therefore, Islamic philanthropy plays a significant role in enhancing the overall well-being of caregivers of children with disabilities, with a particular focus on improving the quality of life among Muslim communities.

### **Conclusion**

It is obvious that Islamic philanthropy plays an important role in enhancing the well-being of caregivers of children with disabilities especially zakat and waqf. These institutions are urged to formulate appropriate strategies as mentioned above to assure the caregivers are able to play effective role of raising children with disabilities who are expected be independent as they grow up. In the long run, they would play vital role to produce independent individual with disabilities (with minimal supervision) in supporting government policy of absorbing workers with disabilities in selected sectors (Act 685 - Persons with Disabilities Act 2008).

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