

Raising Awareness About Autism and Empowering Individuals with Autism: The Potential of Zakat

Shemaila Saleem

Federal Medical and Dental College, Islamabad, Pakistan

Foyasal Khan

UN Capital Development Fund (UNCDF) Bangladesh

Paper to be presented at the 4th International Conference of Zakat (ICONZ)
7-8 October 2020, Surabaya, Indonesia

ABSTRACT

Purpose – This paper aims to study whether Muslim philanthropy is Autism Aware. The purpose of this paper is to assess the potentials of Zakat Funds in the provision of health care services of autistic children and funding autism research.

Design/methodology/approach – This is mainly a desk review of academic, peer-reviewed literature as well as reports published by international organizations and information provided online by governments and non-government organizations.

Findings – A family with Autism Spectrum Disorders (ASD) needs to deploy human and financial resources for the remaining lifetime of the child. Many poor and middle-class families are unable to meet such huge economic burden. Also, ASD research is lacking due to the dearth of research funds. As philanthropic institution, zakat institutions can potentially respond to the autism issue in terms of funding autism research as well as health care delivery to autistic individuals.

Originality/value – In recent years, in the discourse of Muslim value-based public and social policy, Zakat has emerged as one of the important topics. However, no research has been produced on the potentials of zakat in solving autism issue to the best of the researchers' knowledge.

Keywords: Autism Spectrum Disorders (ASD), Socioeconomic Cost, Zakat

INTRODUCTION

Autism is a six-letter word that preferably refers to “Always Unique, Totally Intelligent, Sometimes Mysterious” (Zaky, 2005). The world is full of human diversity. The persons with autism and other forms of disability are parts of it. The new 2030 Agenda for Sustainable Development had been adopted in September 2015 by the United Nations General Assembly. The agenda includes ambitious 17 Sustainable Development Goals (SDGs) and 169 targets. With an envision for achieving an inclusive world, “leave no one behind” has

been a defining principle to the 2030 agenda where the rights, perspectives and well-being of people with autism has also been integrated. Naturally, individuals with autism have a wide range of abilities and different areas of interest. They can contribute to making our world a better place, if their equal participation and active involvement in development process is ensured.

Sadly, many countries simply do not well-understand autism as lifelong condition. As a result, people with autism are ignored in too many societies. Most

importantly, over the last two decades, the prevalence of autism has been increasing and, in many developing and undeveloped countries, resources are so scarce for children that people with autism are being socially and culturally marginalized for life (Edward, 2019).

In recent years, awareness about autism has been increased worldwide to a variety of extent in terms of the seriocomic status of a country. The United Nations is celebrating 'World Autism Awareness Day' on April 2 every year to encourage awareness about autism. In a message on World Autism Awareness Day-2016, the then UN Secretary-General Ban Ki-moon states that young persons with autism are valued members of our diverse human family. Individuals with autism can contribute to a future of dignity and opportunity for all if their rights are advanced and their full participation and inclusion are ensured. Hence, global societies should invest more funds for enabling young persons with autism (UNSDN, 2016).

In this background, this paper aims to study the current global scenarios of Autism Spectrum Disorders (ASD) with special focus on the funding gap for health services in ASD. The specific objective of this paper is to look at how to mobilize zakat (obligatory charity by rich Muslims) in raising awareness about autism and empowering individuals with autism.

The rest of the paper is as follows. Section 2 reviews recent literatures on autism spectrum disorders (ASD) to explore its global prevalence and global efforts to cope with autism and areas need to be focused. Section 3 discusses on Muslim philanthropy in health sector while section 4 describes the applicability of zakat funds in terms of funding autism research and health services in autism. Section 5 concludes.

LITERATURE REVIEW

Autism Spectrum Disorders (ASD) and Its Global Prevalence

Autism is a life-long neurodevelopmental disorder, identified usually in early years of life, characterized by impaired social interaction and communication, limited interests and repetitive repeating patterns (Kuehn, 2007). During the last few decades, research has made it evident that occurrence of Autism Spectrum Disorders (ASD) has become a global concern as the reported number of cases is on the rise. Edward (2019) reports that since 2010, the number of autism population has increased to 15 percent globally. 80 percent of an estimated 70 million individuals with autism are from developing countries. Significant male preference is found among the children who have been diagnosed with autism before the age of 3 and in resource-deficient countries, persons with autism are more socially and culturally vulnerable (Edward, 2019).

Data gathered by organizations contributing to Autism and Developmental Disabilities Monitoring Network, propose that amongst the communities studied, approximately 1 out of 150 children suffer from ASD. Research data from different countries has proposed that the prevalence of ASDs is between 1 in 500 to 1 in 166 (Kuehn, 2007). Elsabbagh et al (2012), in their review article, compares prevalence data from various parts of the world excluding Sub-Saharan Africa. They found that the median global prevalence is estimated to be 17/10,000 (approx. 1 in 588) for autistic disorder. The researchers suggested that the upsurge in the estimates of ASDs over time and the variability of occurrence of ASD cases between countries and regions may be linked to the growing global autism awareness, broadening diagnostic criteria, diagnostic switching and service availability (Elsabbagh et al., 2012).

When considering South Asia, the recorded prevalence of Autism in Bangladesh was 0.2%, 0.84% and 0.15% in

various studies. Two community-based prevalence studies in India reported it to be 0.09% and 0.23%. A community-based study in Sri Lanka showed a prevalence of 1.07% in children aged 18–24 months. Due to the absence of research work on autism in other five South Asian nations (Nepal, Pakistan, Bhutan, Afghanistan and Maldives) the determination of prevalence rate of autism in these countries is challenging (Hossain et al., 2017).

Why Autism is an Important Issue

A family with autistic child has to bear expensive cost of autism treatment and interventions in the lifetime of the child. A case study on Ireland by Roddy & O'Neill (2019) displays that parents play the pivotal role in catering for the requirements of individuals with autism. The average annual cost of an autistic child for their care givers amounted to USD 33,615 associated with private medical care, informal care and lost income. Also, the annual state expenditure for health, social and educational resources of every autistic child costs around USD 16,760 (Roddy & O'Neill, 2019).

When a child is diagnosed with ASD, parents also share the sufferings equally and develop a sense of vulnerability and uncertainty. Medical health professionals understand the complex nature of the disorder and try their best for a better and adequate provision of supportive and treatment modalities (Hahler & Elsabbagh, 2015)

An individual with ASD may not be able to participate in society and conduct daily life activities smoothly. It often negatively influences the person's educational achievements and social fulfilments besides job opportunities. Although a few people with Autism are able to live independent lives but others may have to live with severe debilities and require supportive treatment and care throughout life. The families of individuals with ASDs often have to bear with

significant emotional and economic burden. Provision of care to the children with severe signs and symptoms may be very demanding, especially where access to services and support are inadequate. So, empowerment of caregivers is of prime importance and need of the hour.

Researches on the economic burden of ASD have been carried out mainly in the Western world (United States, United Kingdom, Sweden and China). Leigh & Du (2015) estimates the economic burden of ASD in USA by measuring annual direct medical, direct non-medical, and productivity costs together. Their research anticipates an increase of the economic burden of ASD to \$461 billion (range \$276-\$1011 billion; 0.982-3.600 % of GDP) for 2025 from \$268 billion (range \$162-\$367 billion; 0.884-2.009 % of GDP) for 2015. So, it is important to note here that the economic burden of ASD is likely to surpass that of Attention Deficit and Hyperactivity Disorder (ADHD) and Diabetes by 2025 if the ASD prevalence grows at the current rate (Leigh & Du, 2015).

Studies related to measure the economic costs of autism are almost non-existent in developing and semi-developed countries. Taha and Hussein (2014) addressed the economic burden of Autism in Egypt in recent years. To the dismay it was observed that majority of the individuals with ASD (91.2 %) were dependent on their families for support and care and families were expected to provide care to the ASD individuals life-long. The direct financial cost estimated as a consequence of extensive home-based care ranges from LE 171,368 to 251,303 (US \$31,300–\$45,900) (Taha & Hussein, 2014).

The study of Hasnain & Akter (2014) with a survey of 100 parents of the autistic children who are enrolled in autism schools in Dhaka city revealed socio-economic factors associated with autism among children. The findings showed that autism prevalence was high among children

aged 7-9 years (32%) and 4-6 years (28%). Male children constituted 78% whereas female 22%. Family income was not but education and occupation of parents were associated with ASD. Literacy among the parents of autistic children was poor. 32% illiterate parents followed by 21% parents with primary level education. Regular school-going children was only 38%.

Harman (2014) examines the social, economic, cultural and political factors that impact the experiences of people with ASD. The study interviews seventeen parents of children with ASD and the activities of different ASD-related organizations in Jaipur and New Delhi are semi-structurally observed. The research finds a significant influence of socioeconomic and cultural factors on ASD experiences. The availability of appropriate ASD-related resources is very few in India and the needy people have much less accessibility to these resources. Moreover, social stigma and lack of awareness reduces the quality and accessibility of treatment and intervention. Though many NGOs are working to address these issues, lack of funding and support from the government is a barrier to leverage their efforts.

Individuals with ASD are in deficits innate cognitively, psychologically, or developmentally, in general, in comparison to a common man. However, Harman (2014) finds that social, economic and cultural barriers that a person with ASD is facing is very difficult to manage. A number of social factors aggravate the challenges of ASD in India. Due to the lack of available resources, even for the most financially stable, highly educated, and, socially powerful families, it is very difficult to get early treatment and intervention and other required supports for their children. So, accessing to ASD-related services and resources is more challenging and socially vulnerable for families who are financially unsound, have a lower level of education or live in rural areas. NGOs have so far been playing a key role in raising

awareness and reducing stigma. However, without sufficient government support or recognition, it is almost impossible to provide access to the resources and services to those who need them most (Harman, 2014)

Various studies also show that Autistic children from low-income families are undercounted and underserved. Grupo Salto, a nonprofit organization, was founded in 2003, to serve low-income Spanish-speaking families with autistic children in Chicago. Currently, Grupo Salto is providing support to 500 families. Level of awareness among low-income families about autism is very low. Matie Ovalle, the founder of Grupo Salto stated that many of the families never heard of autism before their child is diagnosed (Alisa Opar, 2019). Hence, Grupo Salto is working for raising awareness through helping the families understand what autism is and what resources are available for them.

Wendy Shaia of the University of Maryland, Baltimore, her son John was diagnosed with autism when he was 2 years old, has been taking services from Grupo Salto. Her realization from bearing the high cost of autism treatment is, in her words, "Because we had resources, John got the services he needed. What about families that don't have the means?" (Alisa Opar, 2019). Similarly, Katharine Zuckerman echoed about the vulnerability of underprivileged families like this "When we have this process that's really complicated, it's always the families with the least privilege who don't make it through."

Due to lack of resources and the competing priorities in survival, low-income and middle-income countries generally prioritize physical health problems over mental health problems and neurodevelopmental disorders especially ASDs (Scherzer, Chhagan, Kauchali, & Susser, 2012). However, it is seen that individuals with ASD can contribute uniquely towards nation building if they

and their families are to be integrated into the mainstream community activities (Harman, 2014). For enhancing the quality of life of the autistic individuals this to happen, building awareness in the society is very important (Harman, 2014; Scherzer, Chhagan, Kauchali, & Susser, 2012). Currently the number individuals and organizations who are dedicated to serve the individuals with ASD is relatively small. The government also should come forward to provide an enabling environment for individuals with ASD (Harman, 2014).

Global Efforts to Cope with Autism and Areas Need to Be Focused

Recent efforts directed to scale up access to evidence-based mental health care delivery in low- and middle-income countries is commendable. The mental health Gap Action Programme (mhGAP) was launched in 2008 by WHO. Mental disorders were identified as one of the prime health problems and developmental disorders as the most important intervention area amongst child and adolescent disorders. It was suggested that there is a dire need to identify the interventions and strategies required for health care support and services and to evaluate the total expenditure for those strategies and interventions (World Health Organization, 2008). (Organization, 2008).

In Global Mental Health Initiative Grand challenges, an association of researchers, clinicians and advocates have publicized research priorities for the following ten years for refining the quality of life of individuals with mental disorders around the globe, and calls for urgent action and investment (Collins et al., 2011). (Collins et al., 2011)

World Health Organization (WHO) developed a The Comprehensive Mental Health Action Plan 2013–2020, which was later adopted in May 2013 by World Health Assembly. It has been proposed that efforts to intensify management approaches for

these disorders should be strengthened and adequate strategies should be defined to materialize the plan. On the basis of targeted global efforts regarding mental health disorders, more focus has been drawn towards ASD as a result of specific initiatives. A consultation on Autism Spectrum Disorders (ASDs) and other developmental disorders was headed by WHO in 2013, which aimed at identifying the research needs and existing challenges in formulating and providing comprehensive care packages for individuals with Autism and other Disability Disorders, and striving to strengthen capacities in various countries via collaborative efforts (World Health Organization, 2013). (Organization).

There is a need to focus on morbidity reduction with parallel developments in identification and adequate health care provision for developmental disorders. In this regard, researchers, practitioners, and policy makers can make a difference. Recently, WHO has stretched out their efforts in the field of autism by developing global level partnerships and taking key international stakeholders on board. At present, more evidence-based research is needed in low- and middle-income countries including the prevalence studies and the clinical trials. Also, there is a need for the implementation of research outcomes to identify the relevance of knowledge gained after the research in High income countries. Unremitting discussions and synchronized efforts by governments, NGOs, United Nations organizations, and civil society are fundamental for the identifying workable approaches for comprehensive and integrated health care service delivery.

a. Funding for Health Services in Autism

Due to the lack of awareness and resources we do not come across many organizations that are providing support to the children with autism. There is very

little data available to support the provision of state funding to individuals with developmental disorders.

Harman (2014) shares the experience of 'Action for Autism (AFA)' as the most powerful, voice of ASD advocacy in India. According to Harman (2014), AFA model has been incredibly effective in making sure that the needs of individuals with ASD are met, while also helping to educate caregivers and establish support systems. Moreover, AFA's public outreach measures have been hugely influential in shaping national policy and attitudes toward ASD.

Health care delivery for ASDs is not well developed. Even in most of the Arab Countries the services are neither accessible nor affordable. National organizations for individuals and families suffering with autism have now been established in various Arab countries. In Saudi Arabia, these organizations and associations encourage voluntary work. Great efforts are being done by various charity organizations in Saudi Arabia but we cannot find any distinct information or volunteering system displayed on the website of Saudi Autistic Society. Also, some organizations have also been established in Egypt to cater for the needs of autistic individuals and people with other developmental or learning debilities like The Egyptian Autistic Society and Learning Resource Center. Majority of them are private and nonprofit organizations possessing experience and expertise in the field. However, underfunding limits the institutional capacities of these organizations (Taha & Hussein, 2014). The few options available for autistic children are extremely expensive and a large financial burden on care givers. Research into the economics of autism in the Arab world is sternly desired (Hassan, 2019).

b. Funding for Autism Research

In the western world, various Non-Government Organizations (NGOs) provide funding for research regarding Autism Spectrum Disorders (ASD) like Medical Research Council, UK, Organization for Autism Research, Autism Speaks, Simons Foundation Autism Research Initiative, Autism Research Institute, Brain and Behaviour Research Foundation but they target a very few specific areas as well as a small population.

A review study conducted in the Arab world scrutinized all research published before January 2014 regarding ASD, it was established that research on autism has been carried out in 13 countries. Most of the research studies were done in Saudi Arabia, with a few conducted in Egypt and Oman. A sum of 142 researches were published from 1992 to January 2014, with a vivid upsurge in publications regarding Autism from the year 2008 onwards (Alnemary, Alnemary, & Alamri, 2017). Despite the progress, there is limited research on ASDs in the Arab world. The factor contributing to the lack of research in the Arab countries is that funding for mental health and related fields is not given a priority by the governments and organizations of the Arab World thus putting a limitation on research concerning ASD (Jaalouk, Okasha, Salamoun, & Karam, 2012).

MUSLIM PHILANTHROPY IN HEALTH SECTOR

An economy may be broadly divided into three main sectors: government (public), commercial (private) and voluntary (not-for-profit) sectors (Ariff, 1991). Religion always plays as a motivating factor for

human being to be engaged in philanthropic or charitable activity under voluntary sector (Osella, Stirrat & Widger, 2015). For Muslims, charity is also a central aspect of an Islamic economy to redistribute income and wealth equitably so that the community's well-being all together can be maximized ((Ariff,1991). Charity in Islam is also a source of social security (Hasan, 2006).

To achieve equity, two major forms of giving in Islam are: obligatory charity (zakat), and permanent endowment (waqf; pl. awqaf) (Hasan, 2006). A waqf is formed through voluntary donation by the owner of a property dedicating the usufruct to some charitable ends (Raissouni, 2001 in Hassan, 2006) and institution of waqf (endowment) can play a significant role in providing common good of all. (Ariff, 1991).

Zakat consists of *zakat al-mal* (wealth tax) and *zakat al-fitr* (poll tax). The latter is commonly referred to as fitrah, which is collected in the month of Ramadhan, prior to Eid celebrations. Zakat, unless otherwise specified, ordinarily refers to wealth tax, although the term may be stretched to cover tax on incomes as well (Ariff, 1991). Zakat is a system of philanthropy practiced all around the globe. It mandates all the eligible Muslims to donate 2.5 percent of their accumulated wealth to the poor and needy. It is one of the biggest wealth transfers to uplift those in need. Muslim faith has succeeded in inspiring the rest of the world as well and Zakat has emerged as a global phenomenon. So, it is not only practiced in Muslim majority countries but is applied in non-Muslim majority countries as well.

Moreover, Sadaqah (spontaneous alms) is prescribed as a supplementary measure in addition to the obligatory tax i.e., zakat. Unlike zakat, which by definition involves financial or real transfers, sadaqah can assume various forms, ranging from cash donations to voluntary services. Thus, sadaqah paly a

significant role in the voluntary sector in the Islamic order.

According to the predictions of Obaidullah and Shirazi (2015), the estimated potential size of annual Zakat pool is between US\$200 billion and US\$1 trillion. Rehman (2018) shows that zakat fund can be used for Sustainable Development Goals or SDGs-related projects. For example, UNDP Indonesia in partnership with the national Zakat collection body, Badan Amil Zakat Nasional (BAZNAS), utilize Zakat funds to enhance people's living standards by accessing them to electricity and the protection of biodiversity. UNICEF and the Islamic Development Bank (IsDB) in collaboration have launched an innovative fund that will open prospects for Muslim philanthropy to provide humanitarian assistance to millions of children for achieving the SDGs. Funding will be disbursed in the provision of education, adequate water and sanitation, satisfactory health and nutrition, early childhood development, protection and youth empowerment (UNICEF, 2019).

The Covid-19 pandemic, started from Wuhan, China, has already turned into humanitarian crisis from its initial health crisis and economic crisis. To deal with the crisis, the governments and voluntary sectors have taken a number of preventive actions. Likewise, as a social organization, the zakat institution has played an important and strategic role to assist the government in preventing Covid-19. Firstly. many people have become new poor caused by weak global economic growth due to Covid-19. These people are new *mustahik* (recipients of zakat) in national and local context (potential recipients) of zakat. To empower them, zakat could be distributed (Al-Anshory, Hudaefi, Junari, Zaenal & Ramdhoni, 2020). However, in global context, this is a high time to discuss opportunities for distributing zakat for the prevention, treatment, and research of Covid-19

vaccines. In this regard, zakat institutions could collaborate with World Zakat Forum (WZF) (Al-Anshory, et al. 2020). Covid-19 pandemic creates opportunities for zakat institutions to expand their role in the education, social and humanitarian sectors (Al-Anshory, et al. 2020). As until now there is no specific vaccine for Covid-19, zakat institution could support the stakeholder of the health sector, both global and national level, to expand its role in conducting its researches and studies that are related to the Covid-19 vaccine (Al-Anshory, et al. 2020). The Rising Sun, a philanthropic organization based in Pakistan, provides home-based rehabilitation service and other services like education, physiotherapy, speech therapy, sensory and hydro integration therapy to children with cognitive impairment like autism and cerebral palsy (Transparent Hands, 2017).

From the preceding discussions, it is clearly evident that the scope of using zakat money has been widened day by day based on the present day needs of the society. Thus, many innovative health-related projects can be developed through zakat money that can open a new horizon to establish Zakat's potential for improving the health sector across the world.

ZAKAT FOR ASD AWARENESS AND EMPOWERING INDIVIDUALS WITH ASD

We have already discussed that there is lack of funding in health services to the individuals with ASD in general and specifically, also lack of funding for autism research. This funding crisis is a barrier to the development of advance treatments and interventions to prevent or smartly dealing with ASD especially in developing countries. In this section, we shall see whether Zakat can be emerged as a potential source of financing the needs of both individuals and families with ASD and funding autism research.

Zakat for Funding Health Services in Autism

The recipients of *Zakat* are regulated in the Quran. According to Surah At-Taubah verse 60, eight groups of *Zakat* recipients are:

1. The Poor (*Al-Fuqara'*)
2. The needy (*Al-Masakin*)
3. Administrators of Zakat (*Al-Amilina Alayha*)
4. Reconciliation of Hearts (*Al-Mu'allafah Qulubuhum*)
5. Those in Bondage (*Fir-Riqab*)
6. Those in Debt (*Al-Gharimin*)
7. In the Cause of Allah (*Fī-Sabilillah*)
8. The Wayfarer (*Ibn al-Sabil*)

The families with autism can be funded from zakat to meet their health services if they fall under three categories of zakat recipients. These are: *Al-Fuqara'* (The poor), *Al-Masakin* (The needy) and *Al-Gharimin* (Those in Debt). The first two categories, the poor and needy, are close to each other and they are very often discussed together. Kahf (2004) argues that income and wealth of both the poor and needy are not enough to cover all their basic needs and they require supplementary support for sustenance. The majority of the *Fuqaha* (scholars of Islamic law) argue that the poor and needy are the main recipients of zakat and they must be given priority so that they can satisfy their basic needs (Kahf, 2004).

Helping those under debts is the sixth category of the recipients of zakat. These debts can arise from natural catastrophes, business practices, borrowing to spend on family needs or from pledging compensational funds. Debts on deceased persons are also included in this category. However, zakat cannot be given to meet the unlawful cause of debts such as gambling or drinking (Kahf, 2004).

To give zakat proceeds to the families with autism, we can broadly categorize a country's population into two groups: Group- A is the population who live below the national poverty line or are

known as poor and underprivileged people while Group-B is the population who live above the poverty line. They may be middle class to rich people. If a family of autism individual falls under Group- A, it deserves zakat being considered in the two categories of Zakat recipients (Al-Fuqara'-the poor) and Al-Masakin-the needy). Whereas, if a family of autism individual falls under Group- B, certainly it cannot get zakat money as the poor and the needy. But it can get zakat money as Al-Gharimin (Those in Debt) because it is revealed from various studies that autism treatments and interventions are so expensive that even a middle class or well-off families face in deep troubles to meet the expenditures and become indebted heavily.

Autism Spectrum Disorder Foundation (2020 website) studied the financial impact of a child with autism. A family with ASD has to bear typically a variety of costs for an autistic child. These families can be supported from zakat money in the following manner.

1. *Zakat for the loss of one parent's income:* Taking care of an autistic children is a huge task. For this, a person needs to be with the child all the time. In many cases parents sacrifice their job to take care their autistic child. In a two-parent family, it is seen that one parent especially mother quit the job and one parent is engaged in earning activities. It is really burdensome for a parent to earn sufficient money to cover family needs as well as maintaining the extensive cost of care. In many cases, they cannot earn that much. So, the loss of one poor and needy parent's income may be compensated from a bringing them under a regular allowance scheme form zakat proceeds.
2. *Zakat for Specialty schooling:* Autistic children often cannot attend in general schools because their learning atmospheres and instruction are different from non-autistic children. Families with ASD needs to bear costly expenditure for providing specialty schools, tutors, and teachers for their children. For low- and middle-income families, bearing such expenditure is very difficult. Hence, the schooling cost of the poor and needy students with autism may be met bringing them under a special scholarship scheme form zakat proceeds.
3. *Zakat for Special activities:* It is important for involving Autistic children in some specialized activities such as special camps, swimming lessons, and social events so that they can learn to function in a non-autistic environment. However, these activities for the social development of their child can be expensive for low- and middle-income families. Zakat fund may be given to the poor families with autism so that they can send their child to these special activities.
4. *Zakat for Special equipment:* Technology has made easy the learning process of Autistic children by inventing specialized equipment to learn even in a non-autistic environment. A recent study has shown that autistic children with the help of iPads are able to communicate and socialize in a non-confrontational environment. But for low- and middle-income families, providing their child with an iPad can be too expensive to bear. So many families are unable to provide gadgets to their child with autism. In this regard, Zakat fund may support them.
5. *Zakat for health coverage:* In developing countries, health insurance is a not a priority for most of the people, let alone Autistic children. Even, many health

insurance companies exclude treatment for autism. To them, behavioral-related therapy is considered not medical rather “educational”. Hence, parents need to pay these treatment costs out-of-pocket which are too expensive for low- and middle-income families. For example, an average cost for occupational and emotional therapy is \$150 per session. Zakat fund may be given to the eligible poor and needy families with autism so that they can buy health insurance for a secured treatments and interventions.

Zakat for Funding Autism Research

We have discussed in previous section that though some organizations are providing funding for research regarding Autism Spectrum Disorders (ASD), they target a very few specific areas as well as a small population. Furthermore, the reason for the lack of research in autism is that the governments across the world are not giving ‘funding for mental health and related fields’ a priority because it is not politically not-so-much demanding to them by the general public. A portion of zakat money can be allocated to promote autism research to improve the living standard of the individual with autism. Spending Zakat proceeds in the way of Allah, the seventh category of recipients, fits for this purpose.

The way of Allah as a category is very wide in scope. Muslim scholars’ opinions in defining this category can be grouped into three. First group believes that any act of general services to Islam or to the Muslim community fall under this category. So, public goods such as bridges, parks, street lights, mosques and other constructions of benefits to the whole community etc. can be provided under this category. The view of second group of scholars is restricted to helping those who are engaged in fighting in a Shari’ah permissible war such as resisting

aggression against Islam itself or Muslims as societies and countries (Kahf, 2004). The third group of Muslim scholars takes a middle position. Their view is that any activities that contribute to the prosperity of the Islamic religion and to making it known to non-Muslim by way of writings, publishing, broadcasting, etc., fall under the category of in the way of Allah (Kahf, 2004).

Due to scientific and technological backwardness, the whole Muslim world is lagging behind in terms of economic and social development in comparison with its western counterpart. Whereas, the Muslim world enjoyed a Golden age from the eighth century to the fourteenth century because of her advancement on cultural, economic and scientific fronts than the rest of the world. In this time of Coronavirus when the whole advanced world is trying to innovate vaccines to contain the pandemic, the role of the Muslim world to this drive is still insignificant. This happens because of not focusing and investing adequately on research and development for a long time. So, Muslim world needs to identify the areas of research and inventions and to invest heavily on these activities if they want to rise again as a global power. We suggest in this paper that autism research may be a potential area where zakat money can be disbursed. A Muslim world zakat fund for health research can be established in this regard.

CONCLUSION

With a staggering increase in Autism, this paper aims to study whether Muslim philanthropy is Autism Aware. We find that since 2010, the number of autism population has increased to 15 percent globally. 80 percent of an estimated 70 million individuals with autism are from developing countries. When a child is diagnosed with ASD, parents also share the sufferings equally and develop a sense of vulnerability and uncertainty. A family

needs to deploy human and financial resources for the remaining lifetime of the child once he/she is diagnosed with autism. An autistic child requires long hours of one on-one interaction with a trained therapist, needs to take costly foods or drug supplements and goes through expensive intervention strategies. Parents require to sacrifice their jobs or engagement in economic activities in order to ensure proper care of their children. Health insurance generally does include to cover the needs of autistic child and there is lack of special education services for them. Research regarding ASD is especially lacking in the developing countries due to the lack of research funding bodies.

So, huge funding is required to cope with the increasing cases of Autism around the world. As philanthropic institution that must be responsive to the global issues, zakat institutions could respond to the autism issue based on several measurable, rational and objective frameworks. This paper, therefore, has laid out the foundation of zakat institution's role in responding autism. Furthermore, we would like to end this paper with several recommendations and policy suggestions for distribution and utilization programs of zakat institutions in health sectors, notably in the context of preventing autism to increase beyond our coping capacity. These are:

- Zakat should be seen as a potential option in terms of funding autism research as well as health care delivery to autistic individuals.
- Government, private and philanthropic sector should come forward to provide funding and support to the individuals with ASDs.
- The relevant government and non-government organizations (NGOs) should aim at providing autism resources and health care services with equitable and affordable access to the health care facilities.

Finally, there is a dire need of commitment and collaboration from all the stakeholders and partners to tackle this public health problem in the nick. The time to perform is now!

REFERENCES

- Al-Anshory, A.C.; Hudaefi, F.A.; Junari, U.L.; Zaenal, M.H. & Ramdhoni, R. (2020), *The Role of Zakat Institution in Preventing COVID-19*, Policy brief, Jakarta: BAZNAS
- Alnemary, F. M., Alnemary, F. M., & Alamri, Y. A. (2017). Autism research: Where does the Arab world stand?. *Review Journal of Autism and Developmental Disorders*, 4(2), 157-164.
- Arif, G.M. (2006), Poverty targeting in Pakistan: the case of zakat and the Lady Health Worker program, In Weiss, J. and Haider, A. Khan. (Eds.), *Poverty Strategies in Asia: A Growth Plus Approach*, Cheltenham, UK & Northampton, MA, USA: Edward Elgar
- Ariff, M. (Ed.). (1991). *The Islamic Voluntary Sector in Southeast Asia*. Singapore: Institute of Southeast Asian Studies
- Autism Spectrum Disorder Foundation (2020 website), The Financial Impact of an Autism Diagnosis, available at: <https://myasdf.org/media-center/articles/the-financial-impact-of-an-autism-diagnosis/>
- Autism Spectrum Disorder Foundation (2020 website), The Financial Impact of an Autism Diagnosis, available at: <https://myasdf.org/media-center/articles/the-financial-impact-of-an-autism-diagnosis/>
- Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum

- disorders. *Psychological medicine*, 45(3), 601.
- Collins, P. Y., Patel, V., Joestl, S. S., March, D., Insel, T. R., Daar, A. S., ... & Glass, R. I. (2011). Grand challenges in global mental health. *Nature*, 475(7354), 27-30.
- Dhaka Tribune (April 1st, 2019). 'Over 47 thousand people living with autism in Bangladesh', available at:
- Edward, O.T. (2019), "Technology can help autistic people live life to the fullest", Published in New Strait Times (Malaysia, April 3). Available at:
<https://www.nst.com.my/opinion/letters/2019/04/475865/technology-can-help-autistic-people-live-life-fullest>
- Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C., ... & Yasamy, M. T. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism research*, 5(3), 160-179.
- Hahler, E. M., & Elsabbagh, M. (2015). Autism: A global perspective. *Current Developmental Disorders Reports*, 2(1), 58-64.
- Harman, K. (2014). Autism Spectrum Disorder in an Indian Context: Impact of Socioeconomic Factors on the Experiences of Individuals with ASD and Their Families. Independent Study Project (ISP) Collection.1954. https://digitalcollections.sit.edu/isp_collection/1954
- Hasan, S. (2006). Muslim philanthropy and social security: Prospects, practices, and pitfalls. *Practices, and Pitfalls (July 10, 2006)*.
- Hasnain, M. G., & Akter, M. (2014). The relation of socio-economic factors with autism among children: a study in an urban area of Bangladesh. *Journal of Pioneering Medical Sciences.*; 4 (1): 11, 13.
- Hassan A. (2019). Arab Views on Autism. *Springer Nature*, 1-5.
- Hassan, M. K. (2006)., "The Role of Zakat in Poverty Alleviation in Bangladesh", Paper Presented at a conference in Dhaka, November 24-26, 2006.
- Hossain, M. D., Ahmed, H. U., Uddin, M. J., Chowdhury, W. A., Iqbal, M. S., Kabir, R. I., ... &
- Hossain, S. W. (2017). Autism Spectrum disorders (ASD) in South Asia: a systematic review. *BMC psychiatry*, 17(1), 1-7.
- Jaalouk, D., Okasha, A., Salamoun, M. M., & Karam, E. G. (2012). Mental health research in the Arab world. *Social psychiatry and psychiatric epidemiology*, 47(11), 1727-1731.
- Kahf, M. (2004). Shari'ah and Historical Aspects of Zakah and Awqaf. *Background paper prepared for Islamic Research and Training Institute, Islamic Development Bank*.
- Kahf, M. (2006), "Role of Zakat and Awqaf in Reducing Poverty: a Case for Zakat- Awqaf-Based Institutional Setting of Micro-finance", Paper for the Conference on Poverty reduction in the Muslim Countries, Nov. 24-26, 2006
- Kuehn, B. M. (2007). CDC: Autism spectrum disorders common. *Journal of the American Medical Association*, 297, 940.
- Leigh, J. P., & Du, J. (2015). Brief report: Forecasting the economic burden of autism in 2015 and 2025 in the United States. *Journal of autism and developmental disorders*, 45(12), 4135-4139.
- Maswood, M. H. (2018), "17 in 10,000 children autistic" in the Daily New Age (Jul 12), available at: <https://www.newagebd.net/article/45831/17-in-10000-children-autistic>

- Muhammad, I. (2019). Analysis of Zakat System in High-Income Islamic Countries. *The Journal of Muamalat and Islamic Finance Research*, 1-11.
- Obaidullah, M., & Shirazi, N. S. (2015). Islamic social finance report 1436H. *Jeddah, Saudi Arabia: Islamic Research and Training Institute (IRTI)*.
- Onaolapo, A. Y., & Onaolapo, O. J. (2017). Global data on Autism spectrum disorders prevalence: A review of facts, fallacies and limitations. *Universal Journal of Clinical Medicine*, 5(2), 14-23.
- Opar, A. (2019). How to help low-income children with autism. Retrieved from: <https://www.spectrumnews.org/features/deep-dive/help-low-income-children-autism/>
- Osella, F., Stirrat, R.L. and Widger, T. (2015) 'Charity, philanthropy and development in Colombo, Sri Lanka.', in *New philanthropy and social justice: debating the conceptual and policy discourse*. Bristol, UK ; Chicago, IL: Policy Press, pp. 137-156. *Contemporary issues in social policy*.
- Rehman, A.A. (22 August, 2018), *Zakat for the SDGs*. Islamic Finance News. Kuala Lumpur, Malaysia
- Roddy, A., & O'Neill, C. (2019). The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed?. *Autism*, 23(5), 1106-1118.
- Scherzer, A. L., Chhagan, M., Kauchali, S., & Susser, E. (2012). Global perspective on early diagnosis and intervention for children with developmental delays and disabilities. *Developmental Medicine & Child Neurology*, 54(12), 1079-1084.
- <https://www.spectrumnews.org/features/deep-dive/help-low-income-children-autism/>
- Taha, G. R., & Hussein, H. (2014). Autism spectrum disorders in developing countries: Lessons from the Arab world. *Comprehensive guide to autism*, 2509-2531.
- Transparent Hands (2017). Providing free medical and Surgical care, Lahore
- UNICEF (2019), UNICEF and the Islamic Development Bank launch first global Muslim philanthropy fund for children [26 Sep, Press Release], New York: UNICEF [Retrieved from: <https://www.unicef.org/press-releases/unicef-and-islamic-development-bank-launch-first-global-muslim-philanthropy-fund>]
- United Nations Social Development Network, UNSDN (2016), Autism and the 2030 Agenda: Inclusion and Neurodiversity, Message of the UN Secretary-General on World Autism Awareness Day 2016, Retrieved from: <https://unsdn.org/2016/04/01/autism-and-the-2030-agenda-inclusion-and-neurodiversity-2/>
- World Health Organization. (2008). *Mh GAP: Mental Health Gap Action Programme: scaling up care for mental, neurological and substance use disorders*. Geneva: World Health Organization
- World Health Organization. (2013). *Autism spectrum disorders and other developmental disorders: from raising awareness to building capacity*. Geneva: World Health Organization.
- Zaky, E. A. (2005). Making a Difference; Celebration of World Autism Awareness Day (WAAD) by Ain Shams University Children's Hospital-Child Psychiatry Team

(AUCH-CPT), April 2016. *Journal of Child and Adolescent Behavior*.

Shemaila Saleem
Associate Professor,
Department of Physiology
Federal Medical and Dental College,
Islamabad, Pakistan
drshemailasaleem@gmail.com

Foyasal Khan
National Consultant, UN Capital
Development Fund (UNCDF) Bangladesh
foyasal.khan@gmail.com