

The Children with Autism Spectrum Disorders in Syrian Crisis: Challenges and Recommendations

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Autism spectrum disorders (ASDs) are a group of developmental disorders, characterized by impairments or delay in functions related to central nervous system maturation, in addition to impairments in social reciprocity, restricted communication, and behavioral Symptoms (WHO, 2013). ASDs is an umbrella that covers Autism, childhood disintegrative disorders, and Asperger syndrome; usually apparent before the age of 3. The World Health Organization (WHO) estimated the ASDs prevalence is 62/10000, that is one child in 160 has an autism spectrum disorder (WHO, 2013).

There is no cure for autism, but different medications, interventions, and programs have been developed to help those children and their families to cope better and manage the symptoms and behaviors. Some of the evidence-based psychosocial interventions are directed to improving the developmental and behavioral aspects and functional adaptive skills, for example: behavior modification interventions, parent-training intervention, and cognitive rehabilitation, training and support (Accessed from: <http://www.cdc.gov/ncbddd/autism/treatment.html>).

While the World Health Organization (WHO) stresses that "People with ASDs have the right to attain the highest standard of health care, without discrimination, in line with Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (CPRD)", however, during the time of civil conflict and war, children with ASD become one of the most vulnerable groups that is highly affected by the crisis, and more common to be forgotten (United Nations, 2006; Accessed from: <http://www.amnesty.ch/de/laender/naher-osten-nordafrika/syrien/dok/2014/humanitaere-krise-in-syrien-die-welt-sollte-sich-schaemen/amnesty-report-left-out-in-the-cold.-syrian-refugees-abandoned-by-the-international-community>)

Prioritizing the care for children with ASD during the time of war is critical. However, this is a challenging mission that is complicated by intertwined barriers of logistic, financial, and structural component.

The most important impediment that hinders the implementation of appropriate intervention to the Syrian children with ASD is the lack of accurate data on their number and locations. Scarce data, adversely, affects the strategic planning and placement of those children in specialized intervention. Additionally, Autism Spectrum Disorders is a group of developmental disabilities extending from mild disabilities such as speech impairment to more severe cases such as intellectual disabilities and autism (Accessed from: <http://www.cdc.gov/ncbddd/autism/treatment.html>). The United Nation High Refugee Committee (UNHRC) estimated that one in five refugees is affected by physical, sensory or intellectual impairment; and that of the 22% of with impairment, 13.4 % have intellectual impairment. Failure to appropriately address the basic needs of those children and helping them accessing adequate levels of assistance will have more severe consequences on their health and wellbeing than the general refugee population (United Nation High Refugee Committee & Handicap International, 2014).

A rough estimate based on the ASD prevalence of 1 in 160

children, as described by World health Organization (2013), and the latest number of children in dire need for humanitarian aid, inside and outside Syria, as reported by UNICEF, which is 7.5 million (Accessed from: <http://www.unicefusa.org/mission/emergencies/child-refugees/syria-crisis>), infers that the number of children on the spectrum of ASD could reach tens of thousands.

An assessment conducted by UNHCR during the second half of the year 2012 on 40,000 Syrian refugees, the findings showed that the potential number of people with disabilities (PWDs) could reach between 4,000 and 6,000 (generally accepted proportion of 10-15% of PWDs in a given population sample). Further studies on the 41 families with PWD, showed that the majority of disabilities were: Speech impairment, cognitive impairment, and motor and/or sensory (United Nations High Commissioner for Refugees, 2014).

In addition to lack of data, the shortage of fund and financial resources imposes a serious impact on providing special treatment, appropriate intervention, recruiting professional, and creating special placement in school for children with ASD (United Nation, 2013).

Impacts of War on ASD Children

Children with ASDs are disproportionately affected by civil war 7. With limited communication, lack of expressive language, and harder adjustments to transition, their reaction will be different toward disastrous conditions in war, and they may express their fears with a wide variety of behaviors, ranging from withdraw to increasing violent and aggressive behavior, or by deterioration in their impairments. In a story, published in autism around the globe (United Nations High Commissioner for Refugees, 2014), a father of severely autistic son in Aleppo, described some of the challenges he encountered while he was in war zone, his autistic son condition deteriorated during the war, after they were forced to end the treatment, and ASDs medical specialists had fled the country, in addition to unobtainable medications, his son used to take. Medications given in ASD are usually prescribed to help in challenging behavior, like anxiety, sleep problems, and hyperactivity, to ease the burden on the family, and make the child more comfortable (Accessed from: https://www.autismspeaks.org/sites/default/files/documents/atn/medicine_decision_aid.pdf).

Additionally, because of cognitive impairment, children with ASD may have difficulty understanding and following the orders in times of urgency situations. Special care should be given to those children, both before and during the urgency, to prepare and direct them toward safety shelters. This include visual schedules, visual aids to alert the strangers of ASD child, due to the sensory distortion of children with ASD, which make them exaggerate their startle response (Asperger's Digest, 2006).

While providing care to children refugees is extremely demanding, helping ASD children in refugee camps would be even more tedious. When refugees with ASD child resettled, they have to face new difficulties caused by economic, social, and environmental factors (Battle, 2014), and without the help of their family or community, their adaptation to the new environment will be extremely challenging. In a report by Amnesty, a four year old autistic child had been left out with his mother and brother for three years after they left Syria and settled in

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a refugee camp in Lebanon, due lack of awareness about Autism and insufficient financial resources to send him to school (<http://www.amnesty.ch/de/laender/naher-osten-nordafrika/syrien/dok/2014/humanitaere-krise-in-syrien-die-welt-sollte-sich-schaemen/amnesty-report-left-out-in-the-cold.-syrian-refugees-abandoned-by-the-international-community>). During armed conflict, displaced children with disabilities rarely are given the accommodations and the attention for their special needs (Battle, 2014). Placement of displaced ASD children in appropriate educational programs that recognize their difficulties and individualize an educational plan should be prioritized. Many of those displaced children never attend school, or discontinued schooling during the relocation, or stopped special treatment program (Battle, 2014). So, integrating them into appropriate school programs that meet their needs, and incorporate them in well structured environments, like school, would enhance their perception and ease the burden on their families.

Furthermore, some Syrian children who fled the country seeking safer places end up in immigration detention centers of other countries. In Australia, as of July 2014, there were 28 children, aged 2-17 years old with disabilities (including children with ASD) spent, on average, 11 months of in detention. Such Prolonged detention resulted in deep adverse effects on the mental and emotional health, and the normal development of those children (Australian Human Rights Commission, 2014).

The Forgotten Victim

Syrian children with ASD have been living the physical and psychological turmoil for more than four years, which endanger their health and well-being. Their lack of expressive language and communication makes them the forgotten victim in Syrian crisis (United Nation, 2013).

To adequately administer the best intervention and place ASD children in the proper program intervention, there should be collaborative efforts between international organizations, (WHO, UNHRC, UNICEF, and Handicap International), and national and local Non-Governmental Organizations (NGOs), as Public-private-partnership, to ensure collecting and sharing data, strengthening the surveillance system, conducting regular assessment on the quality of their living conditions, recruiting trained professionals and therapists, provide the psychological support, and ensure their integration in educational systems.

The lack of awareness about inclusive programs, activities, and policies is relegating PWDs (including ASDs) to a forgotten and excluded group (United Nations High Commissioner for Refugees, 2014). The special needs of children with ASD, both during the urgency situation and the long term special educational programs, should be addressed properly when planning an emergency response by international or local humanitarian agencies (Asperger's Digest, 2006). Promoting the safety and wellbeing of children with ASDs should be one of the top priorities of humanitarian agencies working with Syrian refugees (United Nation High Refugee Committee & Handicap International, 2014; Battle, 2014).

In "The psychosocial care center" located at the border with Turkey, UOSSM (Union of Syrian Medical Relief Organizations) is providing diagnostic tests and individual therapeutic plan to children with special needs, including speech therapy. According to a survey conducted on 770 children in one school, there were 270 with developmental problems, including speech difficulties, learning disabilities, and developmental delay, behavioral disorders, autism. Nine cases of autism, one case in 86 children, were among the 270 developmental problem cases, using the standard international criteria to diagnose these cases.

Several factors interplay in administering successful health care and educational services to Syrian children with ASD, both inside

and outside the country. The most important of which is having strong surveillance system in place and sustainable resources to avoid any interruption.

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