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Statement submitted by Iran Autism Association, a non-governmental organization in consultative status with the Economic and Social Council*

The Secretary-General has received the following statement, which is being circulated in accordance with paragraphs 36 and 37 of Economic and Social Council resolution 1996/31.

* The present statement is issued without formal editing.
Statement

Empowering all women and girls, achievements and challenges

Empowerment is a multi-faceted process that enables individuals and groups with unequal access to resources to gain control over them based on their competencies. Women, specifically, are a key target group in empowerment and poverty reduction efforts. The experience of poverty differs for women, and their empowerment holds significant importance for several reasons. This includes their role in sustaining and managing the family institution, nurturing the next generation, and building their self-confidence. Moreover, women are considered one of the most important indicators of a country’s development status, as highlighted by the United Nations Human Development Index.

Over many decades, there has been a paradigm shift in the perspective on development programs and their strategies. The recognition of women, who constitute half of the population, can no longer be disregarded in development initiatives. However, throughout history, women have often been neglected despite their active involvement in various spheres of production and reproduction.

Numerous studies have revealed that women face higher levels of social discrimination, psychological pressure, and poverty compared to men. Among them, women who assume life responsibilities for various reasons are particularly vulnerable to these challenges.

Among vulnerable groups, priority is given to persons with disabilities, their families, and dependents. Various international instruments on disability emphasize the importance of ensuring the right to health for individuals with disabilities. Additionally, the physical and mental health of relatives, caregivers, and particularly mothers hold significant importance beyond the disabled individual. Mothers of children with disabilities, including those with autism, face ongoing problems and challenges that pose a threat to their physical and mental well-being. Mental health, in particular, is profoundly affected as stress becomes an undeniable and substantial part of daily life for parents of children on the autism spectrum.

Upon learning of their child’s disorder, parents experience a range of emotions. Sadness, worry, doubt, and grief are common during the diagnosis of a child’s autism. Many mothers undergo a prolonged grieving process when their child is diagnosed, and they may initially deny the diagnosis, making it harder to take steps toward improving their child’s condition. These emotional pressures require not only emotional support but also guidance and counselling to navigate the complex journey of autism. The stress experienced by these mothers persists throughout their lives as their children face unique challenges at each stage of development. Consequently, they are more susceptible to depression, with significantly higher rates compared to other mothers.

Mothers of children with autism require empowerment, and one way to achieve this is through participation in parenting education courses. These courses can empower mothers to effectively manage their children’s condition and assist them in developing individual and social skills. Unfortunately, many mothers find themselves caught in a vicious cycle of denial, depression, and anxiety. As a result, the symptoms of autism in their children worsen, further deteriorating the mothers’ mental well-being. In addition to mental health challenges, these mothers also experience various physical problems. For instance, sleep disorders are common among individuals with autism, leading to irregular sleep patterns in their mothers and exacerbating their sleep issues. The fatigue caused by insomnia and chronic stress significantly increases
the risk of conditions such as diabetes, high blood pressure, obesity, heart disease, and other related ailments in mothers of children with autism.

Moreover, these mothers often have limited opportunities to attend to their own physical and mental health. Regular exercise becomes a challenge, and the lack of physical activity and self-care contributes to their fatigue and susceptibility to illness.

Therefore, it holds immense importance to prioritize the physical and mental well-being of these mothers, ensuring they have access to the necessary support and healthcare services. This not only enables them to provide the best possible care and support for their children with autism but also upholds their right to health and overall well-being. Mothers who were previously employed and socially active before their child’s autism diagnosis tend to experience more severe physical and psychological challenges. These circumstances often hinder their ability to continue with their occupational and social activities, leaving them confined to their homes and isolated. As a result, their self-confidence gradually diminishes. The increasing levels of stress and depression among these mothers can lead to feelings of hopelessness and a loss of purpose in life. Many of them express a diminished physical and mental capacity to care for their children, intensifying the challenges they face, particularly in countries with limited access to adequate autism care centres. Moreover, following a child’s autism diagnosis, many families face financial difficulties, as parents may lose their jobs or income due to the demands of caring for their children. This financial strain adds to the burden, making it challenging for families to afford the necessary rehabilitation costs for their children. It is crucial to note that many children with autism require ongoing rehabilitation services to develop their skills and achieve empowerment for social participation. Unfortunately, in some countries, there is insufficient insurance coverage for these rehabilitation expenses.

Therefore, it is crucial to provide ongoing psychological and psychiatric services for both previously employed and stay-at-home mothers. However, it is disheartening to acknowledge that many mothers lack the opportunity for self-care and struggle to access these vital services or cannot afford lifelong treatment expenses.

Responsible organizations and institutions, whether governmental or non-governmental, must prioritize the health and well-being of mothers who care for children with disabilities and physical and mental challenges, including those with autism. Governments should implement comprehensive self-care support plans to assist these mothers effectively. A dedicated budget should be allocated to ensure that mothers, particularly in countries with limited or non-existent care facilities, can benefit from the assistance of caregivers at home for an hour or more. Additionally, these mothers should have regular access to psychological and psychiatric services, either online or in-person, depending on their individual needs. These services would play a significant role in rebuilding their self-confidence and empowering them to lead their children’s individual and social development.

Furthermore, it is essential to provide continuous training in relevant parenting skills to these mothers. Special privileges should be granted to enable their active participation in such training programs. Women’s empowerment necessitates the establishment of essential infrastructures that foster growth in various social, political, economic, educational, and cultural aspects. It aims to facilitate women’s increased and active participation in societal roles, granting them the strength, autonomy, and self-sufficiency to make choices and control different aspects of their lives.

As previously mentioned, many mothers who were once employed have experienced the psychological shock of their child’s autism diagnosis. In addition to this emotional burden, they have also lost their jobs, status, and social connections. It
is crucial to develop specific measures tailored to the needs of these mothers, allowing them to engage in work environments that accommodate their child’s condition. Flexible arrangements, such as remote work or part-time employment, can be viable options for some mothers. Therefore, experts should consider the unique circumstances and limitations these mothers face and devise practical models that enable their presence in work environments.

The Iran Autism Association, which represents approximately eight thousand individuals with autism in the country, urges the international community and all governmental and non-governmental organizations to address the crucial issue of the right to health for girls with autism and mothers of children with autism. The association firmly believes that an informed, confident, strong, and healthy mother plays a pivotal supportive role in the well-being of a child with autism. Without such support, we will witness an increase in physical and psychological problems among mothers, as well as behavioural setbacks in individuals with autism.