



Economic and Social Council

Distr.: General
7 December 2015

Original: English

Commission on the Status of Women

Sixtieth session

14-24 March 2016

Follow-up to the Fourth World Conference on Women and to the twenty-third special session of the General Assembly entitled “Women 2000: gender equality, development and peace for the twenty-first century”

Statement submitted by Agrenska Foundation, 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

The Agrenska Foundation is since 2005 in “Special Consultative Status” with the Economic and Social Council.

The Agrenska Foundation has provided support services to children, adults and their families with rare disorders since 1989. These services include a unique programme of family activities, respite services, education, information projects, and research. Participants in the programs express how their experiences at our program differed from their experiences with the healthcare system.

During the years Agrenska has collaborated with other centres throughout the world. In these collaborations it has become more and more clear that when a family gets a child with a chronic disorder the overall consequences (from a holistic view) are the same regardless where in the world the family lives. If their child has a rare disorder the situation becomes even worse, but it is the same throughout the world. It has also shown that this similarity can be implied regardless of financial or cultural differences.

The Agrenska Foundation wants to state that since all women, and their family, face the same challenges when their newborn child turns out to have a rare and chronic disease, we need to educate how to overcome this worldwide.

The program the Agrenska Foundation and their co-partners have developed is in its structure simple and can easily been applied everywhere in the world.

In 1997 the Department of Economics at the University of Gothenburg conducted a study to evaluate whether the benefits of the Agrenska approach might also extend to healthcare savings. There was, in fact, nearly a three-fold decrease in direct and indirect healthcare costs for families using the Agrenska Centre versus those utilizing only routine support services. The implication is that society and governments can ill afford not to seek new ways to organize support networks for patients with rare disorders.

On May 26th, 2014 Agrenska celebrated our 125th anniversary in the presence of Agrenska Patron, Her Majesty Queen Silvia of Sweden, Mr. Göran Hägglund, Minister of Health, and hundreds of persons representing all areas of society that persons with a chronic disease are depending on in their everyday life.

The start of the “Committee for Rare Diseases” within the Conference of Non-Governmental Organizations next Tuesday, October 20th, 2015 in New York will be a very important platform for bringing knowledge, experience and developing of new knowledge for families who have a child with a rare disease, and their relatives as well as to the wider community.

The United Nations family is a very important organization for this work, and it is with great enthusiasm we look forward to further cooperation with the United Nations Entity for Gender Equality and the Empowerment of Women.