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Committee on the Rights of the Child (the CRC Committee)
Office of the United Nations High Commissioner for Human Rights
Palais Wilson, Office 2-031
Geneva, Switzerland

Submission on General Comment on Children's Right to Health In the CRC Covenant (article 24); Submission by the Ariana-Leilani Children's Foundation International Coalition (Final Corrected)

On behalf of those working to promote the United States ratification of the UN Convention on the Rights of the Child (UN CRC), and the rights of individual children in the USA who are experiencing difficulties in accessing their rights to adequate health care, including physical and psychological care, the following submission is made regarding the General Comment on the Right to Health.

1. What should be the basic premises for the realization of children's right to health?

Attainable standard health is essential to life – both globally and individually. Anything short of this is inhumane, a denial of human rights, and in conflict with the UN Convention on the Rights of the Child (CRC).

Eradicating widespread disease and access to food and water are obvious elements of attainable standard health. However, the basic premises must be more encompassing. The right to health must apply at an individual level, not simply at a macro or group level. Thus, the litmus test for whether "the right to health" is available must be measured for each individual child; otherwise the principles of the CRC – including non-discrimination – will be compromised and rendered null.

The current case of a child in the United States, Ariana-Leilani King-Pfeiffer, age eight years and of German citizenship, demonstrates the problems if "attainable standard health" is not measured at the individual level. Ariana-Leilani King-Pfeiffer is of dual German-American citizenship, currently living in the District of Columbia of the United States of America. The German Government has reviewed her current health condition. For over three years Ariana-Leilani King Pfeiffer has been suffering from untreated toxin/drug induced Severe Chronic Neutropenia, a condition similar to Acquired Immune Deficiency Syndrome (AIDS) that

involves a severely compromised immune system. Just like AIDS, Severe Chronic Neutropenia causes her to risk potentially fatal infections, which when not treated with medicine to boost her immunity, can cause "toxic shock, loss of limbs or loss of life," according to internationally recognized experts. Ariana-Leilani's illness is so rare that she has been listed as one of only about 700 people worldwide on the Severe Chronic Neutropenia International Registry (SCNIR) based in both Germany and the USA. She has also been diagnosed with Post Traumatic Stress Disorder (PTSD). The German Government through its Embassy in Washington, DC has made a formal request to the United States Department of State (Office of Children's Issues) that the latter assist in securing proper medicine and a full independent medical and psychological evaluation for her conditions. These needs have also been recognized by international NGO's, including Innocence in Danger, Worldwide Organization of Women, Children's Rights International Network, and the Severe Chronic Neutropenia International Registry.

The US Department of State claims that it is unable to help this German-American child within its own territorial borders. Thus, Ariana-Leilani needlessly suffers from her health conditions without proper investigative diagnosis and treatment. No doubt if this child were in Germany, her conditions would be actively investigated and treated. The lack of an effective implementation mechanism for the CRC explains the lack of appropriate corrective action in the USA and the non-recognition of her "rights to adequate physical and mental health care", critical to the safety and life of Ariana-Leilani. A child, like Ariana-Leilani, with Severe Chronic Neutropenia could encounter and can succumb to a fatal infection within as little as 18 hours – a shorter period than the time it would take for a child to die from loss of access to food.

The question then becomes "who decides and makes the final decision to assure the right to adequate healthcare"? Such situations must be resolved expeditiously to benefit children like Ariana-Leilani at an individual level regardless where the child is living. The "right to health" must be paramount.

In sum, to help children like Ariana-Leilani, the Comment should define the obligation to assure health at an individual level, so that children, like her, can live a healthy and long life.

2. How can the principles of the CRC, in particular articles 2, 3, 6 and 12, be applied to designing, implementing and monitoring interventions to address child and adolescent health challenges and what aspects are specific to a child's rights approach to health?

Articles 2, 3, and 6 are particularly helpful in designing, implementing and monitoring interventions to address a child's health challenge.

Article 2 requires non-discrimination no matter where the child lives. Thus, a country may not allow different treatment between children who live in a particular province or town within their country, or between those who live inside and those who live outside of the country of their citizenship. As an example, Ariana-Leilani is being discriminated against because a) she is a German citizen (with only a German passport) currently living in the US, and b) the USA does not have, nor enforces, a uniform national children's right to health policy. The German government wants to help Ariana-Leilani, but has been unable to because she is living within the boundaries of the United States.

Article 3 is also helpful because it spells out that the best interests of the child must be the primary concern. It is important to recognize that merely a "due process hearing" does not satisfy the "best interests of the child". The "best interests of the child" must be measured against a substantive objective international standard – not an internal country-specific subjective one. Since the CRC recognizes that children are not property, "parental rights" cannot be allowed to be ownership, and inappropriately override the child's rights to health. Parental "ownership" is often allowed to subordinate a child's human rights; such as it appears to be in the United States of America with Ariana-Leilani

Article 6 goes to the individuality of the right to health – namely that each and every child has a right to live. It would be an abandonment of Articles 2 and 3 if the requirement in Article 6 were not applied at the individual level. Furthermore, the "right to live" can only be enforced while the child is alive. There can be no retroactive restoration for a lost "right to live." Thus, the "right to live" requires that preventative measures be taken to avoid any foreseeable fatal consequences. The right to live is violated if adequate preventative measures are withheld or otherwise not provided. Using Ariana-Leilani as an illustration, her right to live is being denied because proper medical evaluation and treatment are being withheld – which will likely have fatal consequences if the USA authorities do not recognize this child's right to proper health care.

Article 12, the right to have a say, is essential to enforcement. A child must be allowed the opportunity to speak in their native tongue to an independent neutral listener with whom the child clearly understands that there will be no retribution for the child speaking the truth. It also follows that there must be consequences to the child's custodian(s) if the custodian takes revenge on the child for having spoken his or her mind. Again, as illustration, Ariana-Leilani has told social workers, physicians, psychologists and other forensic interviewers that her father "does bad touch," "does naughty touch"; "popo gets harder and harder" sleeps in her "big bed", and that he kisses her "on the lips". She then told others that her father was hitting her very hard and hurts her, and that "papa gives me green medicine to make me sick." Government officials did not listen to her cries for help. Physical and psychological retributions and isolation have taught Arana-Leilani not to speak her mind to others. As a result, she has been effectively silenced over the last three years, not speaking about the present, but only about the past when her health was better and the abuse she endures was not occurring.

Ariana-Leilani is a dual citizen of Germany and the USA. Which member state, Germany or the USA, has the final say for a child like Ariana-Leilani, when her health, and thus life is in danger? Who has the final say when one member state formally recognizes her "right to health" and the other does not? A child's right to health must be of paramount importance. All states must fully and expeditiously cooperate, including the state in which the child resides (here the USA), and allow that "right to health" to be realized and appropriate care provided. With today's highly mobile societies and international travel, such cross-border situations need to be addressed in the implementation so that such "rights to health" are upheld in all countries.

3. What is the normative content of article 24? What are the specific obligations of States under article 24? What are the responsibilities of non-state actors under article 24?

Article 24 provides that children have the right to good quality health care – the best health care possible – to safe drinking water, nutritious food, a clean and safe environment, and information to help them stay healthy. It also provides that rich countries should help poorer countries achieve this. However, "rich countries" must not fail to achieve these goals for the children within their own borders. Rich countries must set the example for themselves and others. Children within their borders often come from other countries. It would be particularly ironic if a child from a "poor" country obtained better health care in their own "poor" country than if they were living in the "rich" country that denies children their right to health.

The failure to provide for children's right to health is not simply a matter of money or access; it is a question of attitude and basic principles. The USA, a rich country, should be held accountable and not ignore children's rights to health within its borders, simply because it focuses its "aid" and attention on children in other countries. Again, Ariana-Leilani's health and life struggles illustrate this point. If she were in a "poor" country, the USA would point to the inadequate health care she was receiving, and the discrimination she was being subjected to, and would probably provide aid to assure that she received adequate health care. However, because she currently lives in a "rich" country, the USA, it is uncritically assumed that her needs are adequately met; not because it is so, but because of where she currently lives.

Finally, the responsibility for assuring the delivery of the attainable standard of health must ultimately rest at the national government level. The international rights to health for each child must supersede jurisdictional issues.

4. What are the priority concerns in general and in particular regions of the world for the implementation of article 24?

Sets of priority concerns should be developed on a country-by-country basis. Each country should enlist NGO's to develop a list of priorities to address the "right to health" concerns of children in their country – on a nationwide basis. Each country, along with the NGOs, should provide reports of those priority concerns, and the progress that is made towards achieving those goals, to the designated UN authority.

5. Which concrete measures should be put in place to implement article 24?

The set of measures will necessarily vary by country context to correspond to their priorities. However, standard model measures should be adopted that are able to show the progress towards meeting each country's' priorities. Even though the USA has not ratified the UN Convention on the Rights of the Child, it should be required to demonstrate a commitment to each child's "rights to health." Children with dual-citizenship (USA) and other countries that have all ratified the CRC (except the USA and Somalia) and who are within the USA borders must have their "right to health" recognized.

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Background:
Under the umbrella of the Ariana-Leilani Children's Foundation International, (www.ariana-leilanifoundation.org) a coalition of partners, organizations and individuals who are active in human rights, child protection, with involvement in the NGO CRC Child Health committee and active in International Health issues have contributed to this statement. What unites them is the interest in enforcement of the CRC in all countries, including the USA and throughout the world. It is their hope that children like Ariana-Leilani will cease being denied effective medical care, so that, even in the USA, too, children's "right to health" are protected.

The contributors include:

Worldwide Organization of Women (WOW), http://www.wowinfo.org, an international non-denominational, non-profit 501 (c)(3) non-governmental organization (NGO). Since December 1997, the Worldwide Organization for Women (WOW) has held special consultative status with the Economic and Social Council (ECOSOC) at the United Nations. WOW has permanent representatives at both the UN in New York and Geneva. Interns from several universities participate in academic training programs and research focusing on issues affecting women and girls worldwide.

Innocence In Danger Worldwide (IID) http://innocenceendanger.org, an international, non-profit association created by a group of citizens on 15 April 1999, at the initiative of the UNESCO Director-General, Federico Mayor, and under the presidency of Ms Homayra Sellier, in response to the recommendations of the UNESCO expert meeting convened in January 1999 on Sexual Abuse of Children, Child Pornography and Pedophilia on the Internet, in order to pursue the objectives of the Action Plan adopted by the experts to combat sexual abuse of children. Innocence in Danger operates in 29 countries throughout the world, with partners who share the same objectives.