



September 12, 2009

## **Position Statement on US Health Care Reform**

International Mosaic Down Syndrome Association believes that all individuals regardless of genetic, medical or physical condition should receive fair and equal health care at an affordable cost.

Currently in America, individuals who have a genetic condition, are considered medically fragile, or have physical limitations are discriminated against through most private and public medical insurance programs.

Individuals with mosaic Down syndrome are automatically disqualified to receive health insurance regardless of their health status or health history unless they were born into an insurance plan. If the family or individual with mosaic Down syndrome loses or changes their job, they are discriminated against and cannot receive new insurance due to their pre-existing condition. The current unregulated insurance often drops coverage of an individual with mosaic Down syndrome once the diagnosis is made, or coverage costs are increased beyond the family's financial limits. If an individual with mosaic Down syndrome receives government health care (ie: Medicaid, Medicare, or public waiver) their medical care is often denied or they are put on a long waiting list to receive medically needed services.

IMDSA believes that health care reform is necessary for those living in America with mosaic Down syndrome and other conditions. However, the proposed health care reform is too vague in its wording and suggests that individuals with mosaic Down syndrome and other conditions will not receive the quality care in which they deserve.

As an Advocacy organization, IMDSA intends on ensuring that proper and concise wording is included in the proposed US health care reform to ensure that individuals with mosaic Down syndrome and other diagnosis and conditions receive:

- Equality in access and cost in health care regardless of diagnosis or condition
- Health coverage which cannot be denied regardless of diagnosis or condition
- Zero exclusions on pre-existing conditions
- Zero exclusions and/or waiting periods regardless of diagnosis or condition
- Health coverage accessibility regardless of job change, geographical relocation, or community status
- Zero caps (annually or lifetime) on medically necessary services which are covered for others without diagnosis or condition
- Coverage that provides necessary therapies that will improve the individual's quality of life such as Physical, Occupational, and Speech therapies.
- Freedom to choose service providers and specialists who are appropriately trained in conditions related to mosaic Down syndrome and other conditions or diagnosis.
- Zero discriminations against those with diagnosis or conditions that may deem medically necessary treatments in which the general population would not require.

IMDSA recognizes that the current US Health Care proposal has included wording to regulate assisted living and nursing home facilities. Because adults with mosaic Down syndrome may require long-term care, IMDSA agrees that regulations are necessary to ensure the safety and quality of life of these individuals. However, because this is a very important part of these individual's lives, and because this type of care is more than just Health Care, IMDSA proposes that any wording on the proposed Health Care Reform that regulates assisted living, nursing homes, or life-time care be in a proposal separate from the Health Care Reform to ensure that individuals will receive the specified care that they need.

In light of this current US health care reform, IMDSA has formed the Coalition for Fair & Equal Health Care. This coalition is designed to bring advocacy organizations together to ensure that all Americans, regardless of genetic, medical or physical condition receive the fair and equal health care that they are entitled to. For more information please contact IMDSA.