

Universal Periodic Review (Upr)
Stakeholder Submission
Autism Rights & Equality Alliance
Ireland
Submission to the United Nations
Universal Periodic Review
Twelfth Session of the Working Group on the UPR
Human Rights Council
6th October 2011

EXECUTIVE SUMMARY

The Autism Rights & Equality Alliance was formed in 2010 by a group of individuals, families and professionals who have a knowledge and understanding of Autism Spectrum Conditions. (AREA) seeks to promote and protect Human Rights through the Universal Periodic Review for Ireland in October 2011 by joint submission. This is the first occasion the Autism Rights and Equality Alliance seeks to interrelate with the United Nations. (AREA) wishes to support the most fundamental freedoms and protections that people are entitled to, because they are human beings..... These Human Rights are Universal , Inherent, Inalienable , Indivisible and Interdependent.

The Autism Rights & Equality Alliance (AREA) seeks to represent a unified voice among the Irish Autism Community; and are prepared to work through the Upr process with the Government of Ireland and the OHCHR to promote a comprehensive plan to address the needs of Irish people with Autism Spectrum Conditions (ASCs) to achieve Equality of Recognition and Non –Discrimination within Disability and Mental Health planning in Ireland through the measurement and collection of Raw Data on Autism Spectrum Conditions in Ireland.

The AREA have identified a number of issues that must be addressed by the Government of Ireland if the rights of individuals with autism are to be established and safeguarded in Ireland and the most basic level of equality of opportunity realised.

There is an urgent need for Government of Ireland to develop a comprehensive Autism Lifespan Strategy for Ireland . Actions must be taken to improve our collective understanding of ASCs, share best practices on interventions, raise awareness and respond to the immense challenges faced by Irish families caring for their family members with autism.

Given the increasing prevalence of autism and the substantial costs incurred by the state when crisis occurs, we feel that the following proposals are both timely from an Economic and a Human Rights Stand Point as the development of appropriate services and supports will lead to less crisis situations and a cost neutral effect on the state.

Current Situation in Ireland in 2011

Supports for individuals with ASCs fall between those offered for individuals with intellectual disabilities and those with mental health conditions. As a result individuals with ASCs do not have their needs recognised or identified or met within the current system in Ireland because they fall between two stools.

Actions to be taken by the Government of Ireland – Pathways to Measured Outcomes Towards Disability Equality Proofing

The (AREA) asks that all Departments within the Government of Ireland recognise that all individuals with ASCs and their families make up a **unique grouping** , that requires services and supports supports based on an in-depth understanding of autism and the challenges living with it presents .

Universal Declaration of Human Rights

December 10 , 1948 adopted by 56 members of the U.N. Non –Binding Document

Regarded as (common standard of achievement for all people and Nations)

Recognition of the inherent dignity and of equal and inalienable rights of all members of the human family is the foundation of the freedom, justice & peace around the world(Preamble).

Priority 2: Data Collection

Current Situation in Ireland in 2011 – No Raw Data on Autism . Autism Spectrum Disorder = Long lasting Disability and Autism merits Recognition as such within the Global Disability Indicators. Not to do so constitutes a fundamental Breach of Human Rights.....Universal , Inherent , Inalienable, Indivisible and Interdependent. Governments are responsible to protect and promote human rights.

Actions to be taken by the Government of Ireland 2011-2016

The AREA asks that the incoming Government of Ireland commits to amending the national census form for 2016 to include relevant questions related to autism.

The AREA asks that the Government commits to a single unified national disabilities database covering all disabilities which has the capacity for monitoring and updating as required.

We request this so that those who do not fit into the traditional tick boxes of the current database systems but who are disabled by a combination of the nature of their conditions and societal barriers are no longer ignored, and services are planned accordingly.

Autism Rights & Equality Alliance Stakeholder Submission Upr Ireland 2011 Priority 3: National Autism Lifespan Strategy

Current Situation in Ireland 2011

In the main individuals with ASCs and their families have to fight for appropriate services and supports. In the absence of a National Autism Lifespan strategy these services and supports are broadly unavailable, piecemeal in nature, and crisis driven and often inadequate and inappropriate. Where services and supports are provided they usually take the form of crisis interventions put in place after the fact which cost the state significant sums economically and place a burden of continuous care on families.

Actions to be taken by the Government of Ireland 2011-2016

The AREA asks and strongly recommends that the incoming Government of Ireland commits to developing and implementing as a priority a National Autism Lifespan Strategy, focusing on the inequalities individuals with ASCs face in education, health and welfare informed by the lived experience of individuals on the spectrum and their families and by internationally recognised best practice. The Autism Rights & Equality Alliance recommends that the incoming Government commits to the development of an all encompassing awareness raising campaign related to the challenges individuals with ASCs face.

Priority 4: Review Funding of Services to People with Disabilities**Current Situation in Ireland in 2011**

The present system of funding for people with disabilities in Ireland is under-resourced, not fit for purpose, does not utilise and build upon the resources and supports within communities, or enable individuals to become active members, and contribute to their communities.

Actions and Recommendations to be taken by the Government of Ireland 2011 - 2016

The AREA requests that the incoming Government of Ireland commits to an alternative resource allocation system that is fair, flexible, equitable and gives people choice – The Autism Rights and Equality Alliance are advocating for a system of Individualised funding or Self Directed Payments to be introduced in Ireland.

Priority 5: Financial Security

Current Situation in Ireland 2011

Today the current reality for many born with a significant disability in Ireland is that they will live a life of poverty. Many families who support and care for their family member with a disability will also live with a reduced income. Parents and other caregivers of persons with disability will also face the uncertainty and anxiety around what will happen if their family member with a disability outlives them.

Actions to be taken by the Government of Ireland 2011-2106

The AREA requests that the incoming Government set up a Disability Savings Scheme for people with disabilities in Ireland similar to the proven systems that have been set up in Canada and the USA. This would signal a shift towards an investment – based approach which would promote self sufficiency and personal responsibility.

International Human Rights Law and Autism.

The Legal Framework and precedence for Protecting individuals on the autism spectrum is solidly part of existing international law and United Nations (U.N.) conventions that protect human rights.

Currently three conventions and one draft appeal cover legal issues and policies affecting our community .

Universal Declaration of Human Rights (1948)

International Covenant on Civil and Political Rights (1966)

International Covenant of Economic, Social and Political Rights (1966)

Declaration on the Rights of Disabled Persons 1975

Convention on the Rights of the Child (1989)

Convention on the Rights of Persons with Disabilities (2007).

Further Priorities

The Autism Rights & Equality Alliance recognises and endorses the work done by other umbrella groups seeking to support those who are disabled societal inequalities and fully backs the following Calls by others interested in the rights and equality of those with Disabilities.

NO MORE CUTS No further cuts to Education and Social Welfare supports. No further cuts to Frontline Services people receive such as respite services. All of these areas have seen cutbacks since 2007. This has led to hardship on people with disabilities and their families; **The Area also calls on the incoming Government to do more to protect those most vulnerable from facing a disproportionate level of cuts to services and supports.**

STANDARDS & INSPECTION There is currently no inspection of disability services for children and adults. Services must be inspected against standards developed by the Health Information and Quality Authority (HIQA);

MODERN CAPACITY LEGISLATION Ireland's current law on decision-making (capacity) dates back to 1871. Modern capacity legislation that provides for supported decision-making must be introduced. This will allow for the ratification of the United Nations Convention on the Rights of Persons with Disabilities;

PUT AN END TO INSTITUTIONS 4,000 people with disabilities live in institutions, many in substandard conditions. The HSE Report on Congregated Settings must be published and an implementation plan on closing these institutions drawn up;

NATIONAL DISABILITY STRATEGY Key parts of the 2004 National Disability Strategy (NDS) have been halted indefinitely. The NDS includes the right to an assessment for children aged 6-18 and for adults. There must be a commitment to full implementation of the NDS, in line with the agreed 'NDS Recession Implementation Plan'
