

Helping the most vulnerable out of the poverty trap and reducing inequality: Policies, strategies, and services for individuals with Autism Spectrum Disorder, including intellectual and neurodevelopmental disabilities.

Description: Autism Spectrum Disorder (ASD) pervasively affects communication and social interactions as well as flexibility in thoughts and behaviour patterns, often but not always with intellectual and/or other neurodevelopmental co-morbidities. While some individuals on the Spectrum are able to function in mainstream society without additional supports, most require intensive services. The estimated prevalence rate across all age groups is approx 1:100. Despite recent advances in brain imagery and discovery of certain genetic linkages, presently there are no medical tests that reliably identify individuals with ASD and consequently diagnosis is based purely on behavioural data, such as direct observations and parental/caregiver reports. Recent studies have estimated that if not adequately treated the lifetime cost to care for an individual with an ASD can amount to as much as \$3.2 million.

In Northern Ireland the new Autism Act (NI) 2011 is aimed at addressing these issues and mandates the development of a cross-departmental autism strategy within 2 years of the Act coming into force.

This proposal is a direct result of previous research by Dillenburger and colleagues on the needs of families affected by Autism Spectrum Disorder in early childhood and futures planning of parents caring for their disabled son or daughter in later life (i.e., 60+ years old). Their most recently completed study on childcare issues across the lifespan clearly pointed towards the need to ensure policies, strategies, and services produce tangible results when combating social exclusion and poverty.

The new 3-year OFMDFM funded research will

- identify and define clearly the issues that arise from the rising rates of ASD and co-morbidities;
- investigate scale and intensity of these issues and develop a system of measurement of need;
- assess access to relevant services, policies, and strategies, e.g., poverty, inequality, education, employment; and
- offer guidance on how to solve known issues as well as problems that had not been identified previously.

The project will be carried out in 4 Phases:

Phase 1 will be a review of relevant policies and strategies from all Government Departments and from a sample of educational institutions and employers.

Phase 2 will be a primary Quantitative Data Collection. A full module of Northern Ireland Life and Times (NILT) Survey will be conducted in collaboration with ARK.

Phase 3 includes Secondary Data Analysis: In order to utilize existing data sets, secondary analysis will be conducted, including all relevant and available data sets, especially with regard to disability and poverty, employment, education, and quality of life measures, and economic impact of policy

Phase 4 is the primary Qualitative Data Collection phase with an emphasis on active engagement, a number of focus groups, interviews, and questionnaire surveys will be conducted with a large number of stakeholders.

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Funder: OFMDFM

Duration: 2012 - 2015