



Autism Action Plan of Canada and Northern Ireland – A comparative review

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ABSTRACT

Autism Spectrum Disorder refers to a range of conditions characterised by some degree of impaired social behaviour, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out in repetition. This paper reviews the Autism Action Plan of two countries, Canada and Northern Ireland and to find out the similarities and differences in their Action Plan and to throw light on their vision, personnel involved (actors) and the policy process. To do this, the health policy triangle has been chosen as a tool to compare and analyse these policies.

Keywords: *Autism Spectrum Disorder, Action Plan, Health Policy*

1. INTRODUCTION

This paper aims to review and compare the Autism Action Plans of two countries. Autism is a condition that was once neglected from the beginning as an important health issue and now it has become an increasingly major public health concern as the number of yearly diagnoses of the condition has increased since the recent years. It is estimated that worldwide, one in 160 children are diagnosed with Autism Spectrum Disorder (ASD) (WHO, 2020).

ASD refers to a range of conditions characterised by some degree of impaired social behaviour, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out in repetition. (WHO, 2020).

Prominent in the first 5 years of age, ASDs tend to persist through adolescence and adulthood. Many factors may lead to ASD, a few of them being genetic or environmental factors with many other co-symptoms like depression, anxiety, attention deficit hyperactivity disorder (ADHD), etc. In 2012, a review of the global prevalence evaluation of autism spectrum disorders found a median of 62 cases per 10,000 people (Elsabbagh et al., 2012).

In this paper, a comparison of the Autism action plan of Canada (Newfoundland and Labrador) and Northern Ireland

has been done. The choice of selection of these countries is because these countries have considered ASD a major health problem and have decided to promote optimal health and well-being for the individuals suffering from ASD and their families and surroundings as well. It is stated that protocols for screening, diagnosis and treatment have increased in recent years in high-income countries whereas the research regarding Autism is very little or unknown in middle and low-income countries (Kamau & Lincoln, 2017). In low and middle-income countries, the focus is more on child health programs mainly on survival issues and very little attention is given to developmental disabilities at policy and implementation level and also it is revealed that budget allocations and human resource development are directed away from these programs (Elsabbagh et al., 2012).

This paper reviews the Action Plan of two countries, Canada and Northern Ireland and finds out the similarities and differences in their Action Plan and to throw light on their vision, personnel involved (actors) and the policy process.

2. METHODOLOGY

To do this, the health policy triangle has been chosen as a tool to compare and analyse these policies. There are many approaches to analyse policy, but this form of analysis narrows down to 4 key questions; why (context), what (content), how (process) and who (actors). Mostly it is used to understand the policymaking process but its components allow for exploration of the content of the interventions, the context in which they are being implemented, the actors involved in the process, and the structures of the process (Walt & Gilson, 1994). The health policy triangle framework analyzes the policy more lucid as it takes into consideration how all the four elements interact to shape the policymaking process.

2.1 Policy 1- Autism Action plan 2019-22 (Canada)

In the first Action Plan, Autism Action Plan 2019-22 (NL, Canada), the vision of the Plan is to support individuals living with ASD and their caregivers to live full and rewarding lives. The 2018 Public Health Agency of Canada in the National Autism Disorder Surveillance System reported that one in 57 individuals in Newfoundland and Labrador are living with ASD. This increase in the number of cases became a health

policy agenda in the country. Hinging on this, the Government decided that there was no single way to resolve this problem and that they needed to incorporate an evidence-based, comprehensive approach to helping the individuals and their families. Hence, a three-year action plan (2020-2022) was devised to bring about the necessary outcome. The actions outlined in the Plan were whole of a government approach with help from the regional authorities and in consultation with individuals living with ASD, family members, community providers, health and education professionals, government agencies and leading researchers in ASD. The Plan aligns with the United Nations Convention on the Rights of Persons with Disabilities whose main purpose is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (UNCRPD, 2006).

Approaching towards the formulation of the plan, the government of Newfoundland and Labrador in affiliation with the Department of Health and Community Services, created an Autism Action Council and the members of this council included the individuals with lived experiences, the Newfoundland and Labrador Association for Community living, health and education professionals, representatives from the department of health and community services, Education and Early Childhood Development, Social Development, Justice and Public Safety and Advanced Education, Skills And Labour department. The Department of Health and Community Services lead the implementation of the plan along with other government departments, indigenous governments and organizations, regional health authorities, schools and community groups. Apart from the Government and other organizations, power was given to the parents, schools, clinicians and first-line staff, etc., as they are in close proximity to those in need and act as their voice and create a sustainable living for the individuals and their families. Creating awareness among all the people regarding ASD gives them an understanding of the problem along with removing the stigma associated with Autism Spectrum Disorder.

The Plan includes six focus areas that are further subcategorized for the implementation process. The six focus areas are Awareness, Acceptance, Diagnosis and Assessment of ASD, Support for Individuals, Families and Caregivers Living with ASD, Evidence-Based Treatment and Management of ASD, Education for Children and Youth Living with ASD, Living with ASD in the Community and Professional Learning and Development in ASD.

The process of implementation of this Plan was done in three phases and the timeline of each of the phases was determined by the urgency of implementation. The following are the phases: Short term (19 actions to be completed by 2020), medium-term (22 actions to be completed by 2021) and long term (5 actions to be completed by 2022). The Plan marks all aspects of individuals living with ASD, including awareness, diagnosis, educational programming and other services that provide support for the affected and their families. The Autism Action Council will be responsible for monitoring the progress of the Plan. An evaluation plan that outlines the desired outcomes will be designed by the Department of Health and Community Services in consultation with the Autism Action Council which will be monitored annually and form the annual progress report. In order to ensure that the Plan aligns with the latest research and evidence, an evaluation will occur after two years to update the Plan accordingly.

2.2 Policy 2- The Autism Strategy (2013-20) and Action Plan (2013-16) - Northern Ireland

In 2010, a school data census in Northern Ireland revealed an increase in the prevalence of Autism Spectrum Disorder which in turn indicated the need to focus more on this issue as a public health agenda (Progress report 2015, 2020). In 2011, a new law was created for Autism in Northern Ireland. The fabrication of this law led to the formation of The Autism Strategy and Action Plan by the Department Of Health And Social Services And Public Safety to improve the support and services for people with autism and their families.

The main stakeholder is The Northern Ireland Human Rights Commission working with other National Human Rights Institutions all over the world through the network of United Nations whose aim is to ensure the promotion of human rights of all people in Northern Ireland and their duty to review the existing law. Hence, due to the formulation of the new and revised law, the Northern Ireland government implemented a cross-departmental Autism Strategy and Autism Action Plan.

The Autism Strategy contains 11 themes that formed the Action Plan within which light was thrown on 16 priorities concerning the delivery of services for the autistic individual and their families or caretakers. The 11 key themes included awareness, accessibility, children, young people and family, health and well-being, education, transitions, employability, Independence, choice and control, access to justice, being a part of the community and finally participation and active citizenship. For each of these themes, different departments or sectors were involved. All government departments such as the Department Of Regional Development, Education, Health, Social Services and Public Safety, Social Development, Employment and Learning And Careers Service, Enterprise, Trade And Investment, Justice and finally Arts and Culture played a crucial role. The Health And Social Care Board and Health and Social Care Trust also played a major role along with the Community and voluntary organisations, local autism groups, Health and Social Care Trust Autism Teams in partnership with the Children and Young People’s Strategic Partnership, Local Councils, Education and Library Boards and the Education and Skills Authority and finally Criminal Justice Agency.

The implementation of the policy was done by establishing a small team focused on performance for each of the 11 strategies individually, gathering performance data and setting targets and trajectories that are ambitious, realistic and evidence-based. All staff or public personnel were trained and educated and made aware of ASD and to treat those individuals with ASD normal. One of the actors was the housing sector which made sure that the individuals with ASD have the opportunity to choose their residence and with whom they live. The transition of the individuals from adulthood to older age was also included in the strategy along with the right to be an active citizen. The National Autistic Society found that only 50% of people with autism in Northern Ireland are in full-time employment even though many can and want to work (Department of Health, Social Services and Public Safety, 2013). Hence, the Department of Employment and Learning was involved in providing further education, training and employment for those with ASD. Data collection was done based on the timeline to ensure that specific measures are properly taken and to enable the stakeholders to formulate and implement more effectiveness in their approach.

The parents, teachers, the clinicians, the neighbourhood and community, the frontline staff, all of them are made aware, educated and trained based on Autism and that those with ASD need to be treated as equal as the normal. So this plan has a hand in each of the important sectors that come in contact with the individual with ASD. The Action Plan was implemented in such a way that each of the 11 themes had their own set of actors and a timeline was set in order to achieve the goals that were set under each criterion. The Plan covered all categories of individuals with ASD right from childhood to adulthood, where they were given the right to be an active citizen as well.

The evaluation of the progress of implementation of the Plan was through direct feedback from the user groups. The Minister of Health, Social Services and Public Safety devised a report prepared by the Department of Health within three years of publication of the Strategy.

3. COMPARATIVE ANALYSIS

Based on the above discussion, both the Action Plans share the same vision, which is to ensure support and wellbeing for individuals with Autism Spectrum Disorder and their families. The Action Plans of both the countries were formulated based on a structural context but the approaches were different. The first policy was formulated in consultation with the people in close proximity with ASD individuals and help from the regional government as well, while the second Action Plan was formulated by the Government of Northern Ireland because a new law for Autism was made. Though the approaches in both the policies were different as in bottom-up in the first Action Plan and top-down in the second, their goal was ultimately the same. The Canada Action Plan emphasised only 6 main strategies and the actors were relevant but in the Northern Ireland Action Plan, there was detailed encryption of each of the 11 themes or strategies and specific actors were allocated for each of the themes along with a timeline. One of the main difference encountered in both the Action Plans were the number of actors and the influence of power. In the Action Plan of Northern Ireland, the key aim was to develop and put in place an infrastructure, at a cross-departmental level, which will ensure that all stakeholders are able to contribute to the delivery of the Action Plan (Department of Health, Social Services and Public Safety, 2013). While in the first Plan, the Autism Action Council which consisted of members in close proximity to the ASD individuals played a major role. Given the first Action Plan, there was a good rapport between the people, regional government and the Government of Canada whilst in the second action plan, it was completely under the influence of the Northern Ireland Executive. Although, the similarities which persisted in both the Action Plans overweighed the differences.

4. CONCLUSION

In Conclusion, Autism requires the attention of not only the parents and caretakers but everyone else in the community as a whole. Furthermore, based on the comparative analysis done on both the Action Plans, the process of identifying the problem and implementing the Plan varies from country to country based on their governments, resources, community involvement, participation and acceptance. Though both the countries have a similar vision in mind, the way they implemented it was similar and different in many ways. In the first plan, few stakeholders were involved whereas in the second plan, each sector was involved. But in the end, both the policies were concerned with creating awareness, empowerment, optimal health and welfare of those individuals with Autism Spectrum Disorder and their families along with recognising their difficulties and trying to make the world a better place for them.

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