## Republic of the Philippines

## **HOUSE OF REPRESENTATIVES**

Queson City

## **EIGHTEENTH CONGRESS**

First Regular Session

HOUSE BILL NO. 1748



Introduced by HON. LUIS RAYMUND "LRAY" F. VILLAFUERTE, JR.

### **EXPLANATORY NOTE**

The word autism can be traced to "autos", meaning salt The word was coined to describe individuals who have "withdrawn within themselves" In medicine, autism, or autism spectrum disorder, refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and non-verbal communication, as well as unique strengths and differences. The disorder includes a wide spectrum, which encompasses individuals who remain nonverbal all their lives, as well as those who manage to enter school and get formal education. At the end of the day, all persons with autism require special attention and expert healthcare.

Rough estimates published by private autism support and focus groups report one million cases of autism in the country, or double its 2008 figures. The sharp spike may be attributed to improved detection, increase in population, or simply, an increase in cases due to environmental and genetic factors. Being a highly variable neuro-developmental disorder, it is not yet full researched or understood in this jurisdiction due to financial constraints.

While there had been several attempts to provide government support to affected individuals and their families, we have yet to establish measures for a truly consistent and comprehensive legislative framework and operational plan to address autism in the country.

It is high time that the State address autism disorder in the country and to institutionalize support for it. First, the bill proposes the creation of a national voluntary registry of children and adults with autism. The voluntary registry will support autism research and public advocacy by providing a rich source of information about families affected by autism, their health and quality of life, as well as their access to services. Second, the bill shall mandate the regular conduct of relevant surveys to determine the extent and total incidence and prevalence of persons with autism in the country in order for the government to provide all the necessary support.

The bill will also address the significant lack of healthcare professionals and experts who are experienced and knowledgeable in the field, consequently reducing the financial burden upon the families who are in need of professional assistance.

An Autism Council of the Philippines, under the Department of Health, is hereby proposed to serve as an inter-agency and multi-sectoral mechanism tasked to promote the implementation of this National Autism Program.

In light of the foregoing, the approval of this bill is earnestly sought.

LUIS RAYMUND "LRAY" F. VILLAFUERTE, JR.

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#### AN ACT

# INSTITUTING A COMPREHENSIVE PROGRAM FOR THE PREVENTION, EARLY DETECTION, DIAGNOSIS, AND TREATMENT OF PERSONS WITH AUTISM SPECTRUM DISORDERS AND FOR OTHER PURPOSES

Be it enacted by the Senate and the House of Representatives in Congress assembled:

SECTION 1. Short Title. — This Act shall be known as "Autism Care Act of 2018".

SEC. 2. Declaration of Principles. — It is hereby declared the policy of the State to protect and promote the right to health of the people, including the rights of persons with autism to full, healthy and holistic development. As such, the State shall promote an environment conducive to the development of autistic persons to become, to the best of their potentials, independent, self-reliant and productive members of society.

Towards this end, the State commits itself to the establishment of institutional and social mechanisms to support children and adult persons with autism and their families. In this light, the State shall institutionalize a holistic program for persons with autism in the country that will be sensitive to their needs for purposes of empowering and providing them quality of life.

SEC. 3. Definition of Terms. —As used in this Act, the following terms shall mean:

- a) "Autism or Autism Spectrum Disorder" refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication, as well as by unique strengths and differences. It includes autism disorder, Asperger syndrome, Rett's syndrome, and pervasive developmental disorders not otherwise specified.
- b) "Diagnosis" refers to medically necessary assessments, evaluations including neuropsychological evaluations, genetic testing or other tests to diagnose whether an individual has one of the autism spectrum disorders.
- c) "Treatment" refers to those that are medically necessary, appropriate, effective or efficient and shall include evaluation and assessment services; behavior training and management and applied behavior analysis; habilitative or rehabilitative care, including occupational, physical or speech therapy; pharmacy care and medication; psychiatric care; psychological care; and therapeutic care.

SEC. 4. Epidemiological Surveillance Programs. — The National Institute of Health (NIH) is hereby mandated to conduct an annual epidemiological survey to determine the extent and total incidence and prevalence of persons with autism in the country in order for the government to provide the necessary and appropriate interventions to address the needs faced by persons with autism.

The NIH is further mandated, in coordination with the Department of Health (DOH), to strengthen its research focus on autism; to renew its investment into basic and clinical research; to expand its research into the link between environmental factors and autism; and to continue investigations into causation, diagnosis, early detection, and treatment of autism spectrum disorders. Such factors that will be studied shall include, among others, infection and immune function, hormonal and reproductive factors, genetic factors, gastro-intestinal factors, and sociodemographic factors.

SEC. 5. Prevention of Conflict of Interest in the Research Process. — Within six (6) months from the date of effectivity of this Act, the DOH shall issue the necessary standards, guidelines, and regulations in order to ensure that there is no conflict of interest, whatsoever, between the research agenda of the researchers and the drug manufacturers or government agencies promoting the use of a particular vaccine or medicine for the treatment and rehabilitation of persons with autism. The DOH shall

ensure the timely publication and dissemination of information of these guidelines and regulations in order to ensure that the various health providers and stakeholders all over the country are adequately informed.

- SEC. 6. Autism Council of the Philippines. There is hereby created an Autism Council of the Philippines ("Council") under the DOH shall serve as an inter-agency and multi-sectoral mechanism tasked to promote the implementation of the National Autism Program of the government. The Council shall endeavor:
  - a) to promote public awareness, education, and information on issues concerning autism;
  - b) to establish sustainable networks of support groups for families of children and adults with autism:
  - c) to provide referral services to patients with autism and identify the appropriate educational and medical expertise and facilities suited to their needs;
  - d) to combat the spectrum of disorders related to autism through screening, education, early intervention, prompt referrals for treatment and services;
  - e) to undertake research and/or collaborate with other entities on research activities regarding autism in the Philippines;
  - f) to coordinate with schools in formulating individualized programs for school children and young students with autism;
  - g) to receive donations and grants from international donor institutions, foundations, and multilateral and bilateral foreign donor agencies involved in the prevention, cure and rehabilitation of persons with autism;
  - h) to promote the advocacy against bias and stereotyping against persons with autism thereby eliminating discrimination and/or misconceptions of the notion of being autistic with the need in being autistic with the need in view of opening the doors of productive economic opportunities to persons with autism;
  - to provide the avenue for exchange for exchange of information, exchange programs and sharing of best practices on issues relating to the early detection, prevention, cure, treatment, and rehabilitation of persons diagnosed with autism;
  - to network with other organizations, institutions, and professionals working for the promotion of legislation and public programs for persons diagnosed with autism; and
  - k) to assist in the creation of appropriate programs for individuals diagnosed with autism.

- SEC. 7. Composition of the Autism Council of the Philippines. The Council shall be headed by the Secretary of Health as the Chairperson. It shall be composed of the following members:
  - a) The Secretary of Social Welfare and Development;
  - b) The Secretary of Education;
  - c) The Chairperson of the Council for the Welfare of Children (CWC);
  - d) The Chairperson of the National Council of Disability Affairs (NCDA);
  - e) The Head of the NIH;
  - f) The Head of the Philippine Information Agency (PIA);
  - g) One (1) representative from the duly accredited association of caregivers in the Philippines; h) One (1) representative from the duly accredited association of caregivers in the Philippines;
  - i) One (1) representative from the duly accredited association of nurses in the Philippines;
  - j) One (1) representative from the duiy accredited association of medical doctors in the Philippines;
  - k) One (1) representative from the non-governmental organizations (NGOs) involved in the advocacy for the prevention, cure and rehabilitation of persons with autism; and
  - One (1) representative from Local Government Units (LGUs) through Union of Local Authorities of the Philippines (ULAP).

The five (5) members of the Council coming from the representatives of the drug and vaccine manufacturers and distributors; caregivers; nurses; medical doctors and non-governmental organizations shall be appointed by the President of the Philippines, from a list of three (3) nominees from each sector, who shall serve for a term of three (3) years, and renewable for another term: Provided, That the person appointed shall be of good moral characters, of unquestionable integrity, and with expertise and experience of at least six (6) years in the field of autism, mental health, and other related fields: Provided, further, That in the event of a vacancy, the successor appointed to fill the same shall serve only the unexpired portion of the term of the member he/she succeeds to.

The members of the Council from the government agencies and institutions ay designate their permanent representatives who shall have a rank not lower than an assistant secretary or its equivalent to attend meetings.

The members of the Council shall receive emoluments as may be determined by the Council, in accordance with existing budget and accounting rules and regulations.

- SEC. 8. Meetings. The Council shall meet at least once a month upon a three-day notice signed by the Chairperson or as often as necessary upon the written request signed by two-thirds (2/3) of its members. The presence of a majority of the members of the Council shall constitute a quorum in order for it to conduct its business.
- SEC. 9. Programs and Services of the Autism Council. The programs and services that will be provided by the Council shall include, among others, the following:
  - a) Orientation and counselling services for families of newly diagnosed with autism;
  - Establishment of Family Support Networks and Sibling Program for families of persons with autism to seek psycho-social support for the various problems they face;
  - c) Establishment of National and Regional Referral Services wherein the Council will update a list of professionals and child care institutions concerned with the case and development of persons with autism;
  - d) Publication of reading materials, manuals, and easily readable instruction materials for autism early detection, prevention, rehabilitation, and care;
  - e) The conduct of continuing education, formation, and training programs and lectures on the proper handling of persons with autism;
  - f) The establishment of a databank and information and monitoring system (IMS) on the demographic, socio-economic, and incidence and prevalence of persons with autism in the country;
  - g) The publication of a newsletter on current developments, resources and research on autism; and
  - h) The conduct of continuing education/training of families, teachers, therapists and caregivers of persons with autism through seminars, conventions and other forms of tri-media educational tools.

SEC. 10. Early identification and Intervention for Children with Autism. — The Council is hereby mandated to establish a program for early identification, screening, and detection of autism, and to provide the appropriate services to children and toddlers with developmental delays associated with autism. The Council is tasked to monitor

and update the list of children diagnosed with autism in the country in its central registry so that such persons may be referred to programs of the government, should the same become available.

SEC. 11. Treatment as Persons with Disabilities. — All persons with autism shall be treated persons with disability as defined under Republic Act No. 7277, as amended. As such, they shall be entitled to all the rights, privileges and benefits provided for persons with disabilities and existing laws.

SEC. 12. Mandatory PhilHealth Coverage. — All persons with autism shall be covered by the National Health Insurance Program of the Philippine Health Insurance Corporation (PHIC). Funds necessary to ensure the enrolment of all persons with autism who are not currently covered under any existing category shall be sourced from the National Health Insurance Fund of PHIC earmarked from the proceeds of tax collections as provided for in Republic Act No. 10351. It shall likewise include the cost of early detection and screening programs as one of the available benefits of its members.

SEC. 13. Continuing Education and Training of Health Personnel and Service Providers on Autism. — Ali DOH, DSWD, CWC, NCDA officers and their staff in charge of providing various developmental and welfare services to persons with autism are mandated to undergo a mandatory continuing education and training program to sensitize and empower service providers to become effective frontliners in the delivery of health services to persons with autism.

SEC. 14. Protection against Forcible Use of Cures and Vaccines. —The DOH shall formulate the necessary guidelines, standards and procedures against the forcible use of cures, vaccines, and therapies to persons diagnosed with autism in order to uphold the right of every individual to give informed consent to medical treatment administered to them as well as to protect their right to determine for themselves the medical treatment to which they shall be subjected.

The DOH shall promulgate guidelines and standards to ensure that the interventions and programs being provided by the government for persons diagnosed with autism do not violate their basic human rights, particularly as regards their rights to determine their own decisions.

- SEC. 15. Protection against Discrimination in Schools. The Department of Education (DepEd), in coordination with the DOH, Department of Social Welfare and Development (DSWD), and CWC, and the NIH, shall formulate the necessary implementing rules and regulations to ensure that all educational institutions shall be free from policies and regulations discriminatory to school children and young students suffering from autism. Towards this end, the DepEd shall conduct an annual staff to empower them to effectively handle school children and young students suffering from autism.
- SEC. 16. Non-Discrimination of Adults Suffering from Autism. Within six (6) months from the date of effectivity of this Act, the Council shall formulate the necessary guidelines, standards, and regulations in order to ensure that adults with autism are not discriminated against due to their condition. The Council shall ensure the timely publication and dissemination of information of these guidelines and regulations in order to ensure that the various stakeholders all over the country in the early detection, prevention, rehabilitation, and care of persons with autism are adequately informed.
- SEC. 17. Confidentiality of Medical Information for Persons with Autism. To ensure that the early detection, screening tests, vaccination, medical treatment, and rehabilitation of persons suffering from autism are implemented, the DOH, in consultation with the Department of Justice(DOJ), shall formulate the pertinent implementing rules and regulations to ensure the confidentiality of the medical records of persons suffering from autism in order to protect the unwarranted intrusion into the privacy of the person, particularly in relation to the medical condition of the patient.
- SEC. 18. Appropriation. The amount necessary to carry out the provisions of this Act shall be included and incorporated in the annual general appropriations of DOH.
- SEC. 19. Implementing Rules and Regulations. Within six (6) months from the effectivity of this Act, the DOH, in coordination with the DSWD, DepEd, CWC, NIH, NCDA and PIA, shall promulgate the necessary implementing rules and regulations to implement the provisions of this Act.
- SEC. 20. Separability Clause. If any section or provision of this Act is held unconstitutional or invalid, the other sections or provisions shall not be affected.

SEC. 21. Repealing Clause. — All laws, Presidential decrees, executive orders and rules and regulations, or parts thereof, inconsistent with the provisions of this Act are hereby repealed or modified accordingly.

SEC. 22. Effectivity. — This Act shall take effect fifteen (15) days from the date of its complete publication in at least two (2) newspapers of general circulation.

Approved,