

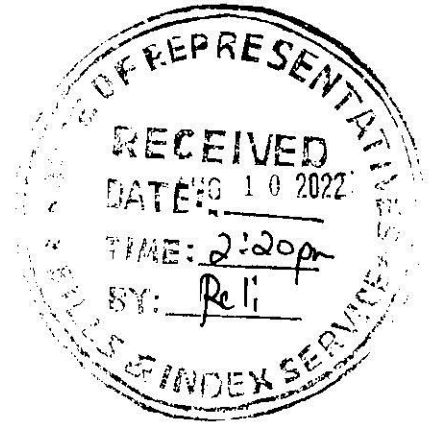


Republic of the Philippines
House of Representatives

NINETEENTH CONGRESS

First Regular Session

HOUSE BILL NO. 3462



Introduced by Rep. Luisa Lloren Cuaresma
Lone District of Nueva Vizcaya

**AN ACT PROVIDING FOR THE BENEFITS AND PRIVILEGES TO PERSONS WITH
DOWN SYNDROME BY CREATING AN OFFICE UNDER THE DEPARTMENT OF
HEALTH AND APPROPRIATING FUNDS THEREFOR**

EXPLANATORY NOTE

Republic Act No. 7277, otherwise known as “The Magna Carta for Disabled Persons” that was approved in 1992 was promulgated to ensure that the State will be able to give its full support to the improvement of the total well-being of disabled persons and aid in their integration into the mainstream of society.

The said law has been amended several times by numerous other laws, administrative orders, local ordinances, department circulars, rules and proclamations to improve the welfare of persons with disabilities or the PWDs.

However, inspite all of the amendments, the existing laws, projects and programs are not comprehensive and specific enough to translate the laws into concrete and sustainable progress of the PWDs in the country.

This proposed legislation seeks to establish a system that will help ensure the welfare and well-being of persons with Down syndrome in the Philippines through the establishment of an office under the Department of Health.

Down syndrome (DS), also known as **Trisomy 21**, occurs when an individual has a full or partial extra copy of chromosome 21. A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. An individual with Down syndrome may possess these characteristics to different degrees, or not at all. People with Down syndrome experience physical growth and cognitive delays but they possess unique strengths and talents, attend school, work, and participate in decisions that affect them, have meaningful relationships, vote and contribute to society in many wonderful ways.

Despite such mental, verbal and intellectual hindrance, the state recognizes the potential of persons with Down syndrome in labor and various vocations in par with their conditions making them valuable assets for the development of the state.

The Office for Persons with Down Syndrome shall supervise the implementation of a research program not only to provide health care information, provisions for early and sustainable care and to conduct public educational and information campaigns on Down syndrome but also to research on careers better suited for persons with Down syndrome.

This Bill also seeks to provide fiscal and regulatory incentives to therapists, developers, teachers, manufacturers, and importers of medicines, medical devices, diagnostic kits and other pharmaceutical and nutritional products needed by patients with from Down syndrome.

This Bill shall ensure that patients with Down syndrome have better access to adequate education, medical care, health information, and health care products needed to treat their condition. It establishes a system to coordinate a sustainable research & development initiative and resource generation efforts among relevant agencies of the government and the private sector toward improving the quality of life of patients with Down syndrome and their families.

In view of the foregoing, the passage of this bill is earnestly sought.

Luisa Lloren Cuaresma
LUISA LLOREN CUARESMA



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

SECTION 1. Short Title - This Act shall be known as the "Down Syndrome Act"

SECTION 2. Declaration of Policy – It is the policy of the State to protect and promote the right to health of the people and instill health consciousness among them. Towards this end, it shall develop various program tailored to persons with Down syndrome and their parents or guardians by providing them a comprehensive package of health, education and social development.

To facilitate full development and support patients with Down syndrome, the State shall exert all efforts to remove all health, social, cultural, economic, and environmental and attitudinal barriers that are prejudicial to people with Down syndrome and to recognize what assets they can be in State development.

SECTION 3. Objectives – The objectives of this Act are as follows:

- 1) Ensure that every patient diagnosed with Down syndrome and their parents or guardians to have access to timely health information and adequate medical care, including therapists, medical services and other health care products to treat or otherwise help them cope with their condition;
- 2) Establish an office within the Department of Health:
 - a. To oversee research & development activities on Down syndrome and determine their capabilities beneficial to society;
 - b. To design and maintain a rare disease registry which shall include data on Down syndrome in the Philippines; and
 - c. To conduct public education programs to identify persons with Down syndrome and help the public understand not only with respect to their needs but also to make the public know they can still adapt well and be an integral part of society.
- 3) Provide regulatory and fiscal incentives to support research and development activities on Down syndrome, educators who specialize on persons with Down syndrome, therapists who specializes in Down syndrome and the importation or manufacturing of affordable medicines for persons with Down syndrome; and
- 4) Institutionalize a financial incentive system for agencies involved in clinical research, patient care, medical information management and other similar activities for the benefit of persons with Down syndrome.

SECTION 4. Definition of Terms – For the purpose of this Act, the following terms shall be used under the definition provided hereof, to wit:

- a) *“Healthcare practitioner”* – Any doctor of medicine, dentist, therapists, nurse, midwife, allied health professionals registered under Professional Regulatory Commission;
- b) *“Healthcare institution”* - refers to hospitals, health infirmaries, health centers, therapy centers, lying-in or puericulture centers whether public or private;
- c) *“Medical care”* – means any method used by health care practitioner to prevent, diagnose and remove symptoms and cause of disease;
- d) *“Down Syndrome Registry”* - shall mean health information system maintained by the Department of Health (DOH), including the electronic database system, relating to data on Down syndrome, persons with Down syndrome, health practitioners that treat persons with Down syndrome, Heath institutions that provide medical services and therapies for persons with Down syndrome and list of medical products that are needed by persons with Down syndrome; and
- e) *“Down Syndrome”* – is a chromosomal condition caused by the presence of all or part of a third copy of chromosomes 21.
- f) *“PWD Underparent”* – Any person who directly provides parental care and assumes parental responsibilities to a Person with Disability (PWD) or a court appointed guardian, who is duly appointed by the Board of Evaluators hereinafter created;
- g) *“Person with disability”* - a person suffering from restriction or different abilities, as a result of a mental, physical or sensory impairment, to perform an activity in a manner or within the range considered normal for human being.

SECTION 5. Creation of Office for Persons with Down Syndrome – There shall be an Office for Persons with Down Syndrome under the Department of Health (DOH) to oversee research & development activities on Down syndrome, to design and maintain a Down syndrome registry which shall include data on Down syndrome in the Philippines, patients with Down syndrome, health care practitioners that treat persons with Down syndrome and medical services and drugs for persons with Down syndrome.

SECTION 6. Composition of the Office –The Office for persons with Down syndrome shall be a collegial body headed by the Assistant Secretary of the DOH as chairman, one representative each from the Department of Social Welfare and Development, Bureau of Food and Drugs, the National Institutes of Health, a national support group, a private healthcare company, a member of the academe, and a representative from the Department of Justice as members and lastly, a representative from the DSWD as the secretariat.

SECTION 7. Duties and Functions of the Office – The Office shall have the following duties and responsibilities:

- 1) To enforce the provisions of this Act;
- 2) Recommend agenda for the conduct and support of research and development initiatives on Down syndrome, health care and products to identify relevant research opportunities;
- 3) Promote coordination and cooperation among institutions involved in researches on Down syndrome;
- 4) Enter into agreements with and award research grants for centers for researches doing studies on Down syndrome;
- 5) Prepare annual reports describing the research & development activities supported by the Office, and identifying projects that should be conducted in the future on Down syndrome;
- 6) Evaluate activities of the National Institutes of Health in the management of information system and ensure that Down syndrome registry is current and useful;
- 7) Ensure appropriate coordination among interested agencies, manufacturers and organizations representing patients afflicted with Down syndrome;
- 8) Inform health practitioners and the public regarding the availability of treatments and medicines;

- 9) Promote the development of updated treatment guidelines on the approach to persons with Down syndrome;
- 10) Establish a referral system to facilitate the provision of appropriate medical care to persons with Down syndrome;
- 11) Liaise with national and international patient, health and scientific organizations working on Down syndrome;
- 12) To conduct case studies and evaluation to the different conditions affecting the persons with Down syndrome and their families;
- 13) To investigate any violation of this Act or of the rules and regulations issued thereunder, as may come to the knowledge of the Board and for this purpose to issue *subpoena* and *subpoena duces tecum* to alleged violators or witnesses to secure their attendance in investigations or hearings, and the production of books, papers, and documents in connection therewith and compel attendance by the power of contempt;
- 14) To conduct yearly examination and evaluation of social health workers to assigned in every DSWD field office;
- 15) To look, from time to time, into the conditions affecting the persons with Down syndrome and their parents or guardians;
- 16) Adopt measures as may be deemed necessary to ensure inclusion of persons with Down syndrome in the society;
- 17) To provide for reasonable accommodation and accessible environment for persons with Down syndrome;
- 18) To advocate respect and awareness about the efforts made to improve the quality of life of persons with Down syndrome and their families;
- 19) To research on viable occupations well suited to persons with Down syndrome; and
- 20) To make the public know that they can adapt and be an integral part of the mainstream society.

SECTION 8. Supervision of the Board and Custodian of Records – The members of the Board shall be under the direct supervision of the DOH. All records, including examination papers, evaluation reports, minutes of deliberation, records of administrative cases and investigations of the Board shall be kept by the Secretariat of the Board.

SECTION 9. Incentives for Down Syndrome Funding and Resource Generation – The following shall be exempted from all taxes whether national or local:

- 1) Donations to the Office of persons with Down syndrome and the National Institutes of Health intended for research on Down syndrome, maintenance of Down syndrome registry or for purchase of drugs, products for use solely by persons with Down syndrome;
- 2) Procurement of drugs and products for use solely by persons with Down syndrome, as certified by the National Institute of Health;
- 3) Healthcare facilities that directly provides therapy for persons with Down syndrome.
- 4) Drugs and products donated solely for persons with Down syndrome shall be exempt from payments of all tariffs and duties.

SECTION 10. Flexible Work Schedule - The employer shall provide for a flexible working schedule for employees with Down syndrome. Provided, that the same shall not affect individual and company productivity.

SECTION 11. Work Discrimination - No employer shall discriminate against any employee with respect to terms and conditions of employment on account of his/her condition as a person with Down syndrome or the status of his/her dependent having Down syndrome, provided that they do not impede work productivity, and provided further that the nature of their work is not detrimental to their condition.

SECTION 12. Parental Leave - In addition to leave privileges under existing laws, parental leave of not more than seven (7) working days every year shall be granted to an underparent employee who has a dependent with Down syndrome and who has rendered service of at least one (1) year.

SECTION 13. Emergency Parental Leave – In addition to parental leaves, an underparent may also be given emergency leaves in times when his/her child or ward is experiencing uncontrollable behavior, severe tantrums, seizures or other cases as determined by the Department of Health.

SECTION 14. Incentives for Employer - To encourage the active participation of the private sector in promoting the welfare of persons with Down syndrome and to ensure their gainful employment, adequate incentives shall be provided to private entities which shall employ persons with Down syndrome.

SECTION 15. Educational Benefits. - The Department of Education (DepEd), Commission on Higher Education (CHED) and Technical Education and Skills Development Authority (TESDA) shall provide the following benefits and privileges:

- 1) Scholarship programs for qualified persons with Down syndrome in institutions of basic, tertiary and technical/skills education; and
- 2) Special Education (SPED) Tutorial programs appropriate for persons with Down syndrome.
- 3) Ensure that persons with Down syndrome are provided with adequate access to quality education and ample opportunities to develop their skills.
- 4) Ensure that public and private educational institution shall take appropriate measures to make such education accessible to all persons with Down syndrome.
- 5) Ensure that the public and private educational institutions shall take into consideration the special needs of persons with Down syndrome in the formulation of educational policies and program, facilities, class schedules, physical education requirements and other factors pertaining to their condition.

The DepEd, CHED and TESDA shall promulgate rules and regulations for the proper implementation of this program.

SECTION 16. Vocational Rehabilitation - Consistent with the principle of equal opportunity for disabled workers and workers in general, the State shall take appropriate vocational rehabilitation measures that shall serve to develop the skills and potential of persons with persons with Down syndrome and enable them to compete favorably for available productive and remunerative employment opportunities in the labor market.

The State shall also take measures to ensure the provisions of vocational rehabilitation and livelihood services for underparents in the rural areas. In addition, it shall promote cooperation and coordination between the government and non-government organization and other private entities engaged in vocational rehabilitation activities.

The head of TESDA shall design and implement training programs that will provide persons with Down syndrome with vocational skills to enable them to engage in livelihood activities or obtain gainful employment. The Department of Labor and Employment shall likewise design and conduct training programs geared towards providing persons with Down syndrome with skills for livelihood.

SECTION 17. Vocational Guidance and Counseling - The Department of Social Welfare and Development shall implement measures providing and evaluating vocational guidance and counseling to enable persons with Down syndrome to secure, retain and advance in employment. It shall also provide training for underparent based on the nature of disability of his/her dependent with Down syndrome. It shall ensure the availability and training counselors and other qualified staff responsible for the vocational guidance and counseling of underparents.

SECTION 18. Vocational or Technical and Other Training Programs

The State shall provide persons with Down syndrome with training in civics, vocational efficiency, sports and physical fitness, and other skills. The Department of Education, Culture and Sports shall

establish in at least one government-owned vocational and technical school in every province a special vocational and technical training program for persons with Down syndrome. It shall develop and implement training program specifically designed for persons with Down syndrome.

SECTION 19. Role of National Agencies and Local Government Units - Local government units shall promote the establishment of organizations of disabled persons in their respective territorial jurisdictions. National agencies and local government units may enter into joint ventures with organizations or associations of disabled persons to explore livelihood opportunities and other undertaking that shall enhance the health, physical fitness and the economic and social well-being of underparents and persons with Down syndrome.

SECTION 20. Implementing Rules and Regulations. - The Department of Health shall formulate, within ninety (90) days upon the effectivity of this Act, the implementing rules and regulations in consultation with the local government units, nongovernment organizations and people's organizations.

SECTION 21. Authority of Court - The court may grant any equitable relief that such court considers to be appropriate, including, to the extent required by this Act:

- 1) Granting temporary, preliminary or permanent relief;
- 2) Providing an auxiliary aid or service, modification of policy, practice or procedure, or alternative method; and
- 3) Making facilities readily accessible to and usable by individuals with disabilities.

SECTION 22. Penal Clause - Any person who violates any provision of this Act shall suffer the following penalties:

- 1) For the first violation, a fine of not less than Fifty thousand pesos (P 50,000.00) but not exceeding One hundred thousand pesos (P 100,000.00) or imprisonment of not less than six (6) months but not more than two (2) years, or both at the discretion of the court; and
- 2) For any subsequent violation, a fine of not less than One hundred thousand pesos (P 100,000.00) but not exceeding Two hundred thousand pesos (P 200,000.00) or imprisonment for less than two (2) years but not more than six (6) years, or both at the discretion of the court.

Any person who abuses the privileges granted herein shall be punished with imprisonment of not less than six (6) months or a fine of not less than Five thousand pesos (P 5,000.00) but not more than Fifty thousand pesos (P 50,000.00), or both, at the discretion of the court. If the violator is a corporation, organization or any similar entity, the officials thereof directly involved shall be liable therefor. If the violator is an alien or a foreigner, he shall be deported immediately after service of sentence without further deportation proceedings.

SECTION 23. Appropriations. - The amount necessary to carry out the provisions of this Act shall be included in the budget of concerned government agencies in the General Appropriations Act of the year following its enactment into law and thereafter.

SECTION 24. Repealing Clause. - This Act shall apply suppletory to Magna Carta for Persons with Disability as amended and other existing laws. All laws, decrees, executive orders, administrative orders or parts thereof inconsistent with the provisions of this Act are hereby repealed, amended or modified accordingly.

SECTION 25. Separability Clause. - If any provision of this Act is held invalid or unconstitutional, other provisions not affected thereby shall continue to be in full force and effect.

SECTION 26. Effectivity Clause. - This Act shall take effect fifteen (15) days following its complete publication in the *Official Gazette* or in at least two (2) newspaper of general circulation.

Approved,