

## The Role of Government and NGO in Promoting Wellness of People with Down Syndrome

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### ABSTRACT

People with Down Syndrome (PWDS) experience cognitive delays indicated by difficulties with cognition, long-term memory and non-verbal problem solving skills. PWDS have specific speech and language impairments which affect all aspects of development. Some children develop difficult behaviors which cause family stress and affect social and educational inclusion. These deficits are worsened by a higher incidence of certain medical problems which were extensive from birth to old age. Being intellectually challenged, PWDS face many challenges and barriers to care for themselves, to lead rich and varied lives as well as to get involved in all aspects of community life. Besides helping them to assume responsibility for their own wellbeing, it is upon dedications from all parties to assist them to live a longer life expectancy with dignity and wellness intact. This paper aims to understand the scope of wellness for PWDS and the hindering factors as well as identifying contributions towards wellness of PWSD, its flaws and suggestions for improvement. The analysis and discussion is grounded in the context of Malaysia against the backdrop of PWDS across nations. It found that People with Disabilities (PWD) in Malaysia are protected by different laws and acts.

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## 1. INTRODUCTION

Down syndrome (DS) is a common chromosomal disorder due to an extra chromosome number 21 (trisomy 21), which is characterized by recognizable facial features, impaired cognitive ability, gross and fine motor skills, language, etc [1]-[3]. The incidence of DS is about one in every 733 birth in United States [4] and one per 950 births in Malaysia (USM Human Genome Centre and Genetic, 2013) [5],[6]. The breakdown of the number of People with Down Syndrome (PWDS) are Indonesia, 298,066, Malaysia, 29,403, Singapore, 5,442, Phillipines, 107,802, Thailand, 81,081, Vietnam, 103,328, United States, 367,069 [7].

PWDS are categorized as people with Intellectual Disability (ID). Down syndrome accounts for almost 40% of cases of moderate to severe learning disabilities and is a lifelong condition [8]. 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. Every PWDS is a unique individual and may possess these characteristics to different degrees or not at all.

PWDS have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most PWDS lead healthy lives. Life expectancy for PWDS has increased dramatically in recent decades - from 25 in 1983 to 60 today.

Despite having longer life expectancy, at least half of all children and adults with DS face a major mental health concern during their life span. Children and adults with multiple medical problems experience an even higher rate of mental health problems. NDSS (2012) report the most common mental health concerns include general anxiety, obsessive-compulsive behavior, oppositional, impulsive and inattentive behaviors, sleep related difficulties, and neuro-psychological problems characterized by progressive loss of cognitive skills [5].

Most young and early school age children have limitations in language and communication skills, cognition, and non-verbal problem solving skills. Older adults showed increased vulnerability to generalized anxiety, depression, social withdrawal, loss of interest, and diminished self-care, decline in cognitive and social skills and dementia.

In some developed countries, the welfare of PWDS are systematically planned to ensure wellness in their lives. In developing countries such as Malaysia, Acts and provisions are created to protect PWD but for the category of DS, much has to be done for this intellectually challenged group who are marginalized in many aspects of their lives. In Malaysia, the government and in particular, the Ministry of Education and Ministry of Women, Family and Community Development, as well as NGO: the Malaysian Down Syndrome Association (PSDM) at national and state levels and Kiwanis Down Syndrome Foundation are institutions that provide assistance to children with DS.

This paper will discuss 4 main parts related to the wellness of PWDS: (1) What is wellness for PWDS? (2) What are the hindering factors to achieve wellness for people with PWDS? (3) Contribution from the Government and NGO towards wellness of PWDS.

## 2. WHAT IS WELLNESS FOR PWDS?

Wellness is an active process of becoming aware and making choices toward a healthy and fulfilling life. "It is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (The World Health Organization).

Wellness is not just absence from illness but encompasses much more than that. National Down Syndrome Society, New York (2012) identified wellness as combination of six main areas of life: the intellectual, physical, emotional, social, psychological and spiritual [5]. University of California (2012) listed seven dimensions to contribute to wellness: social, emotional, spiritual, environmental, occupational, intellectual and physical wellness [9].

From the perspective of PWDS, their voices and writings reflect their hope to be truly accepted by the society at large and valued. Grace (2005), a high functioning adult with DS chose the title "I Am Human, Not Alien" on her book which could translate into her dreams to be given fair treatment. Her writings tell what wellness meant to her, as well as other PWDS [10]:

"We may be different to you on the outside, but we feel the same on the inside."

"I feel that not being accepted by society is tearing me apart because we are human beings too who don't deserve to be treated this way."

"I don't want to waste my entire life making pompoms and capping bottles. I want to learn something and make use of my brains."

Down Syndrome Association (DSA) across the globe is working relentlessly to champion the rights of PWDS. To summarize their mission statements, it is about the wellness for PWDS which covers every aspect of their lives to help ensure that they live a meaningful life with full inclusion rather than exclusion. Among the wellness statements implicated in their mission statements:

- i. DSA of United Kingdom: to help PWDS to live full and rewarding lives
- ii. Canadian Down Syndrome Society, CDSS –To empower Canadians with DS and their families by raising awareness and provide information on Down syndrome through the prenatal, early childhood, school years, adulthood, and retirement stages of life
- iii. DSA of Queensland - to build community awareness of DS and to support, advocate for and empower PWDS to take their rightful place as valuable and contributing members of their local and global community
- iv. ISDI (Ikatan Sindroma Down Indonesia or Indonesian Down syndrome Society) - to prepare children with DS by giving them various vocational trainings to suit their abilities and guiding them to reach their maximum potentials. This way we hope they will be able to live independently and be free of the negative label they are carrying now. So life seems to be bearable and the horizon seems to open up to give way for a bright and fruitful futures.

- v. Kiwanis Down Syndrome Foundation, Malaysia - committed to the welfare of children with Down Syndrome, its main focus being the education of these children up to 6 years old.
- vi. DSA of Malaysia, Persatuan Sindrom Down Malaysia (PDSM) - To integrate, collaborate and build partnerships with the government, corporations and general public to generate awareness and compassion towards the Down Syndrome community.

In a nutshell, wellness for PWDS takes a few aspects, interrelated and interacts to contribute to the quality of their life as follows:

- i. Physical wellness: to maintain a healthy quality of life that allows them to keep themselves through daily activities without undue fatigue or physical stress and healthy eating habits. It also implies individuals take responsibility for their own health care such as caring for minor illness and knowing when professional medical attention is needed
- ii. Social wellness: the ability to interact with people around them. It involves their ability to establish and maintain meaningful relationships with family members and friends through good communication skills, respecting themselves and others.
- iii. Emotional wellness: the ability to understand and cope with their own thoughts, feelings, and behaviors, whether positive or negative
- iv. Environmental wellness : ability to have a meaningful experience in schools, family, and community
- v. Occupational wellness: the ability to get personal fulfillment from jobs while still maintaining balance between work and leisure time, addressing workplace stress and building positive relationships with co-workers and contribute positively to the organization that employ them
- vi. Sense of accomplishment: the ability and freedom to rejoice own accomplishments, to feel their hard work and dedication being appreciated in visible ways and feels the desire to continue their effort

Sense of self-esteem: ability to see the differences between themselves and their peers without DS, maintain a sense of self-worth and keeping a positive self-image

### 3. WHAT ARE THE HINDERING FACTORS TO ACHIEVE WELLNESS FOR PWDS?

To live with dignity is deemed as a basic right for everyone. For PWDS, it takes their own awareness to assume responsibility to achieve the so-called rights to live a meaningful life while people who are working with them to advocate for their rights. There are many uncontrollable internal factors which are intertwined with external factors, mostly uncontrollable that are inhibiting wellness of PWDS. Among these are the developmental deficits in cognitive abilities, language, communication and speech; health condition; and their social emotional behaviours.

#### 3.1. Physical fitness and health status

PWDS have certain physical deficits which may hamper their movements. They develop motor skills at a slower rate than typically developing peers (Vicari, 2006) which is detrimental to the acquisition of other related activities in education, vocational and recreational (Jobling, 1998) [11],[12]. Their physical development may be affected by their health status. A few health profiles of PWDS as summarized by Pitetti, Baynard and Agiovlatis (2013) are shown in Table 1 and Table 2 [13].

**Table 1. Description, demographics, and health profiles of persons with Down syndrome**

Characteristics	Description
Description and demographics	1. Caused by trisomy 21
	2. 11.8 per 10,000 births (USA)
	3. Mild/moderate intellectual disability
	4. Limited adaptive skills
	5. Life span near 60 years
Health profiles - Childhood	1. Congenital heart disease (septal and valvular defects)
	2. Respiratory illnesses (pneumonia and chronic bronchitis)
Health profiles - Adulthood	1. Deterioration of functional capacities due to dementia of Alzheimer's type
	2. Recurrent pneumonia
	3. Sensory impairments (hearing and vision)
	4. Musculoskeletal disorders (joint instability and osteoporosis)

Table 2. Physical fitness in youth with Down syndrome (DS)

Characteristics	Description
Cardiovascular fitness	<ol style="list-style-type: none"> <li>1. Low peak aerobic capacity/time to exhaustion</li> <li>2. Low peak heart rate</li> <li>3. Peak aerobic capacity does not change significantly with age after w16 years</li> <li>4. Autonomic dysfunction a primary factor related to low fitness</li> <li>5. Field tests largely support laboratory findings</li> <li>6. Responsive to aerobic endurance training, particularly with improvements in work capacity</li> </ol>
Muscular strength	<ol style="list-style-type: none"> <li>1. Lower strength compared to individuals without disabilities</li> <li>2. Resistance training appears safe and beneficial for improving strength</li> <li>3. Improved leg strength does not appear improve aerobic capacity</li> </ol>
Body composition	<ol style="list-style-type: none"> <li>1. Youth with DS in North America and Europe are more obese/overweight vs. counterparts without disabilities</li> <li>2. Cause of high rate of overweight/obesity is multifactorial (physiological, societal, environmental, psychological, etc.)</li> <li>3. Studies show no improvement in body composition from exercise training alone, likely due to lack of dietary control.</li> </ol>

Individuals who are working to promote the physical fitness of PWDS have to plan appropriate physical activities by considering the characteristics of physical health, cognitive and psychosocial which are limiting their physical fitness and physical activity. Despite the predisposition attributes, Pitetti, et al., (2013) recommended physical activities to improve the cardiovascular, metabolic, musculo-skeletal, and psychosocial health profiles of all youths [13]. Well designed programs should take into account the physical, cognitive, and psychosocial health profiles of PWDS as well as their need for enjoyment and participation.

### 3.2. Cognitive factor

All PWDS experience cognitive delays which are varied among individuals. PWDS accounts for almost 40% of cases of moderate to severe learning disabilities and is a life long condition [8]. Delay in cognitive development (e.g. speech, language, auditory short-term memory) DS is another concern [14]. Short-term memory was found as the significant factor influencing language and comprehension skills acquisition (Laws *et al.*, 2004) and the core problems identified among individuals with DS were impaired working memory and executive functioning (Lanfranchi *et al.*, 2010) [15],[16]. Short-term memory span predicts their subsequent vocabulary development and the verbal short-term memory has been related to the ability of an individual to learn the meaning of unknown words [17].

PWDS have specific difficulties in learning language. Delays in language, communication and speech are profound in children and adults with Down's syndrome [18]. Speech and language skills are more delayed than the children's non-verbal understanding and reasoning abilities [19]. Most children with Down syndrome understand more language than they can use as a result of specific speech production and hearing difficulties. For this reason, learning to sign will help the majority of children to communicate, to show their understanding and reduce their frustration. For most children with Down syndrome, the most serious delay that they experience is in learning to talk. This is not only frustrating but it has serious consequences for all other aspects of their social and cognitive development.

In speech, there is considerable difficulty at all levels from planning to articulation and phonology. Most teenagers still have significant intelligibility problems [20]. Expressive language is generally found to be much more impaired in individuals with DS than receptive language or comprehension and non-verbal cognitive skills [21],[22].

Deficits in memory, processing skills, and expressive language affect the communicative competence of children and interactions with families, peers and community members. These shortcomings are barriers for them to communicate their thoughts and feelings of sadness, anger, loneliness and their needs effectively to others, and therefore hampering their connectivity with others.

### 3.3. Social emotional factor

Social development includes social interactive skills with children and adults, social understanding and empathy, friendships, play and leisure skills, personal and social independence and socially appropriate behavior [23]. Social functioning is regarded as strength for individuals with DS. Most children and teenagers with DS have age-appropriate behavior, but some children do develop challenging behaviors with many being referred as 'stubborn' or 'obstinate' [18]. As summarized by Reynolds (2010), these challenging

behaviors are associated with some negative behaviors such as self-injury, damage to the physical environment, prevent learning of new skills and socially isolate the learner [24].

Children and teens with DS would want to have their own circle of friends just like their peers without DS. Social interaction involves ability to communicate, to understand the behavior, emotions and feelings of others. These success factors in social interaction are obviously lacking among PWDS. Many individuals with DS may have additional difficulties to establish friendships due to their social incompetencies as well as speech and language and cognitive delay.

### **3.4. Family environment**

From birth, parents are the closest ones to children with DS. All children are influenced by their experiences with their parents, siblings, and other personalities who are close to them. This interpersonal experience varies within families. As a basic need for every individual, children with DS too would want to fulfill their basic needs for warmth, love, food and care. For families which are socially disadvantaged such as unemployed parent (s), single parent, or poor families, their children will tend to have more risk for developmental difficulties [23].

Besides disadvantaged family background, some parents may have poor parenting skills or have difficulties to adapt to becoming parents of a child with disability, thus influence the progress of the child. If parents do not get support from outside, the task of bringing up children with DS may be emotionally straining especially for the mother. In addition, parents who have inappropriate expectations and requirements for good behaviour and their inability to manage behaviour of the child with DS may influence the development of the child. Without family support and understanding, the child with DS may fall behind their peers in many developmental areas and resulting in difficulties to cope with the demands from schools, thus falling further in acquiring academic and non-academic skills. For some children, behaviour is not easy to change and if a child is persistently difficult in school and at home, parents and teachers will have to work together to develop common strategies in order to change the behaviour [23].

## **4. CONTRIBUTION FROM THE GOVERNMENT AND NGO TOWARDS WELLNESS OF PWDS IN MALAYSIA**

Although many children with DS are able to become an integral part of family, peer, community and work environments, success in such situations is often hampered by challenging behaviours (Feeley & Jones, 2008) and health conditions. It is therefore of paramount importance to have targeted strategies to help them to face challenges in their lives [18].

In Malaysia, there are agencies, organizations, corporate sectors and individuals who are giving financial aids and services to improve the life of PWD. There are four main government agencies involved in the services for PWD [25]: (1) Ministry of Health, (2) Social Welfare Department under Ministry of Women, Family and Community Development (MWFCDD), (3) Ministry of Education, and (4) Labor Department. Besides these agencies, there are NGO that provide services for the PWD. There are big corporations that are actively involved in Corporate Social Responsibility (CSR) activities. The 10MP (Tenth Malaysian Plan) encourages the private sector to implement CSR programs and also explicitly identifies national commitments towards children. In the last decade, a few Laws and Acts were passed to protect the rights of PWD in Malaysia.

### **4.1. Laws and Acts**

In Malaysia, a number of policies were generated to secure the rights of PWD. The National Welfare Policy 1990 is aimed at creating a stable and secure society, and giving equal opportunities to PWD. The National Social Policy 2003 focused on defending the equal rights of PWD and full participation in society. The National Policy for Persons with Disabilities 2007 focused on the well-being of PWD. The introduction of Persons with Disabilities Act 2008 was a significant move for people with disabilities. It contains comprehensive rights and welfare for PWD, including promotion of quality of life and wellbeing, public facilities and services, employment, housing and rehabilitation. Persons with Disabilities Act 2008 clearly states that 'persons with disabilities shall not be excluded from the general education system on the basis of disabilities, and children with disabilities shall not be excluded from pre-school, primary, secondary and higher education, on equal basis with persons or children without disabilities, including vocational training and lifelong learning' (p.24). The National Plan of Action for Persons with Disabilities (2007-2012) emphasized on positive attitude, barrier-free environment, user-friendly transportation, health service,

rehabilitation, education, employment, roles of NGO. It stated the 1% policy on employment opportunities for PWD in the public sector.

#### 4.2. Significance of guideline for better health and personal growth

There are several medical concerns that are specific to Down syndrome, or at the very least, occur in much higher incidence than in people who do not have the condition. However, with proper identification, information, and treatment of the medical issues of children with Down syndrome, most people with the condition live a fairly long and health life.

Life expectancy over age 55 exists for at least 50% and beyond age 68 for 14% of the DS population [26]. Early access to services and clinical intervention, as well as inclusion in the community, have increased life expectancy from 12 years in 1940 to 60 years in 2006 [27]. Roizen and Patterson (2003) pointed that individuals with DS are prone to attacked by congenital heart defects, diabetes, depression, Alzheimer's disease, and thyroid disease [28]. Therefore, individual with DS are at the high risk of mortality than that of their peers with intellectual disabilities and normal people [27]. Although pneumonia, or other types of respiratory infections, was the most common cause of death across the entire lifespan, ranging from 23% of deaths in adulthood to 40% in senescence, each life stage exhibited a particular profile of comorbidities. Congenital heart defects were found as the second common cause of death (13% of deaths in childhood and 23% in adult) [27].

Due to the developmental and health difficulties of individuals with DS, it is necessary to better understand the life quality and health problems of this population. Cohen (2009) summarized a health screening and consultation guidelines from US to help family and parents having DS children keep optimal well-being of this population (Table 3) [29].

Table 3. A health care guidelines for individual with DS from US [29]

Age	Health supervision recommendations
0	Confirm the diagnosis by Chromosomal karyotype evaluation; Cardiac evaluation (including echocardiography); Objective hearing evaluation (auditory brainstem response test or evoked otoacoustic emission testing); Ophthalmoscopic examination to detect dense congenital cataracts; Thyroid function testing (check state-mandated screening); Early Intervention consultation ("Birth to Three" developmental services) Discussion about the available family support; Medical genetics consultation (discussion of future risk in subsequent pregnancies) Repeat hearing evaluation by 9–12 months with behavioral audiometry.
1 year	Eye examination at 6 months. Repeat thyroid function testing (thyroid-stimulating hormone and free thyroxine) at 6 and 12 months. Hearing evaluations per 6 months until pure-tone audiograms can be obtained for each ear separately, then, examine hearing by year. Eye examinations;
1-12 years	Thyroid function testing every year Dental care every 6 months, beginning at 2 years old. Obtain lateral cervical spine radiographs (flexion, neutral, and extension), measuring the atlanto-dens interval and the neural canal width, between 3 and 5 years old to look for atlantoaxial instability. Screen for celiac disease at 2 years old with immunoglobulin A tissue transglutaminase antibody and total immunoglobulin A levels. Thyroid function testing per year.
adolescence	Vision, hearing assessments and dental care; Adolescent medicine consultation about sexual health concerns. Educational programming should focus on transition planning.

As shown in Table 3, beside some specific items related to check-ups and disease screening, early intervention for individual with DS was recommended since they were born. It usually covers a broad range of developmental training and therapies such as physical therapy focusing on motor development, speech and language therapy, occupational therapy, and sensory integration therapy. At the age of 3, children with DS are eligible for preschool education and they need extra help in school; while the continuous individual intervention is still suggested to ensure master the basic self-management skills, social and emotional skills. At the age of 7, children with DS are expected to enroll in local mainstream schools with inclusive education or special education. At the age of 20 to 23, they may be eligible to accept post-secondary education or training for the future employment. After the successful post-secondary training, individuals with DS are able to get appropriate job and fully or partially support their life.

### 4.3. Government contribution in education for PWDS

In Malaysia, the special needs students are categorized into three main disabilities: the hearing impaired, the visual impaired and the learning difficulties/disabilities students. Students with DS fall under the category of learning disabilities (LD). The basic education for all students in Malaysia is 11 years but for students with disabilities (in Malaysia, they are known as learning disabilities/difficulties, LD or Students with Educational Needs, SEN), they are given 13 years of free education – one year preschool, six years primary, three years of lower secondary and 3 years of upper secondary education and extra 2 years either at the primary or secondary level. The extra two years are given to help them acquire more skills to meet their needs in future.

The government of Malaysia is committed to ensure the rights of SEN in formal education as embodied in the Education Act 1996 which states that “all pupils with special needs who are educable are eligible to attend the special education program. Article 28 of the Persons with Disabilities Act 2008 states that ‘Persons with disabilities shall not be excluded from the general education system on the basis of disabilities, and children with disabilities shall not be excluded from pre-school, primary, secondary and higher education, on equal basis with persons or children without disabilities, including vocational training and lifelong learning [30],[31].

Education for SEN continues to improve under various Acts and provisions. The Persons with Disabilities Act 2008 states that ‘persons with disabilities shall not be excluded from the general education system on the basis of disabilities, and children with disabilities shall not be excluded from pre-school, primary, secondary and higher education, on equal basis with persons or children without disabilities, including vocational training and lifelong learning.’ The recently launched, Malaysia Education Blueprint 2013-2025 aims to have 30 percent of students with SEN will enrol in inclusive program by 2015. The goal shows how serious the ministry is in implementing inclusive education. Inclusive education provides the least restrictive environment which is ideal for the development and progress of SEN such as students with DS. As explained by Winter (1999), inclusive education environments are designed to provide an educational setting in which all students can be as involved and independent as possible [32].

For those more ‘abled SEN’, they could further their education to tertiary level or taking various certification or diploma courses with full sponsorship. In the case of students with DS, there aren’t any who have made it to diploma or university levels. Opportunities for higher education remain bleak for them due to their cognitive delays and other confounding physical and intellectual factors. Unless serious educational measures are planned and carried out for students with DS, there won’t be any one to chart the graph for higher education in Malaysia.

### 4.4. Financial assistance and other services [33]

- 1) **Launching Grants (Geran Pelancaran)** - To assist persons with disabilities who have the knowledge and skills but who do not have the financial capital or equipment for self-supporting / small business / agricultural projects. Maximum Launching Grant - RM2,700.
- 2) **Disabled Worker’s Allowance (Elaun Pekerja Cacat EPC)** – Working allowance of RM300 per month is provided to encourage persons with disabilities to continue working and be self-supporting without depending on their family or others, and to obtain supplementary income for their basic necessities.
- 3) **Assistance with Purchasing National Vehicles** - Persons with disabilities who can drive are given up to 10% off the sales tax of National cars/motorcycles. Applications can be made directly with the Ministry of Finance (Kementerian Kewangan) together with the following documents: Medical report, doctor certification, Identity Card for Persons with Disabilities, IC, a valid driving license and vehicle details (model, engine number, chassis number etc.)
- 4) **Telekom Assistance** - Telekom Malaysia provides assistance to the disabled in the form of: exemption from monthly phone rental rates, free-of-charge 103 operator calls, and call waiting / call divert services.
- 5) **Tax Relief and Exemptions** - Tax relief/exemptions are provided for parents who have children with disabilities below the age of 18 years. Tax deductions are given for the purchase of special equipment for personal use or for the use of children/parents with disabilities. Tax deductions are also given to employers of the disabled. Additional tax exemptions are given to person and spouses with disabilities.
- 6) **Public Transport Assistance** - Amongst others, MAS gives up to 50% discounts on domestic airfares, KTM provides up to 50% off all classes of rail travel, TRANSNATIONAL busses gives up 50% discounts of ticket prices, and PUTRA-LRT also provides discounts for the disabled.
- 7) **Housing Assistance** - Kuala Lumpur City Hall (DBKL) also provides the disabled with rental assistance for low-cost housing and DBKL flats.
- 8) **Exemption from Medical Treatment Bills** - Persons with disabilities are exempted from paying for third-class wards, specialist bills and medication.

- 9) **Exemption from Travel Document Bills** - The Immigration department provides exemptions from costs of preparing and processing travel documents (International passports).
- 10) **Derivative Pension** - The government, through the Public Service Department's Pensions Division, has approved a derivative pension for children/dependants of civil servants who have passed away.
- 11) **School allowance** - Monthly allowance of RM150 to students with disabilities in primary and secondary schools
- 12) **Registration and Identity Card** - The purpose of registration is to collect data and statistics for the planning of services, rehabilitation programs, prevention, training, education and early intervention. The Identity Card for Persons with Disabilities (Kad Kenal Diri Orang Kurang Upaya) are issued to those who register themselves to make communication with the relevant authorities easier.
- 13) **Assistance with Orthotic/Assistive Devices (Bantuan Alat Tiruan/Otortik)** - The purpose of this is to help persons with disabilities purchase orthotic/assistive devices such as wheelchairs, calipers, artificial limbs and other equipment they cannot afford. These devices will allow them to be mobile and to continue with the activities of daily living.
- 14) **Sheltered Workshop (Bengkel Terlindung)** - The Welfare Department will try to obtain job opportunities for the disabled in the private/public sector, or placement in Sheltered Workshops such as Bengkel Daya Klang, Bengkel Daya Sg. Petani, or any of the 13 other workshops run by voluntary organizations.
- 15) **Vocational Skills Training** - Bangi Centre for Rehabilitation and Industrial Training (Pusat Latihan Perindustrian dan Pemulihan Bangi) - Diploma-level courses and MLVK (Majlis Latihan Vokasional Kebangsaan) Certification are offered for persons with physical disabilities aged between 18 and 40 years, who have passed at least a PMR or equivalent level, and are independent. Courses offered include computers and secretarial, tailoring and fashion design, manufacturing of assistive devices, computer support, electrical wiring, electronics, baking, photography and driving.
- 16) **Entry into Rehabilitation Institutions (Taman Sinar Harapan)** - Rehabilitation is given to persons with intellectual disabilities to acceptable levels based on individual capabilities and desires. Shelter and care are also provided for persons with severe disabilities. Activities include training daily living skills, pre-vocational education, informal academic classes, religious/moral lessons, sports/recreation and outdoor activities.
- 17) **Community-Based Rehabilitation CBR (Pemulihan Dalam Komuniti PDK)** - CBR is a community development strategy for persons with disabilities to obtain rehabilitation within their family and community whereby they are given the equal opportunity for rehabilitation and interaction with society. Activities include gross motor skills, fine motor skills, language development, social development, self-care, pre-Reading/Writing/Math skills, creativity, sports and recreation.
- 18) **Training and Rehabilitation Assistance** - The Social Welfare Department provides skill training and rehabilitation programs in its institutions for children with disabilities. At this time, only children with intellectual (learning) and physical disabilities are eligible for services.
- 19) **Assistance with Prosthetic / Assistive Devices** - The government provides exemption from import duties and sales tax for equipment designed specifically for use by persons with disabilities.
- 20) **Job Opportunity Assistance** - The government's commitment to provide job opportunities for the disabled includes the allocation of 1% of all public sector jobs. The Department of Labour (Jabatan Tenaga Kerja) also provides registration services of job opportunities for the disabled.

#### 4.5. NGO's contribution

NGO that are predominantly providing resources, contribution and services towards PWDS as follows:

- 1) **Kiwanis Down Syndrome Foundation, KDSF** - The *Kiwanis Down Syndrome Foundation* has nine branches nationwide and playing the role as the most significant NGO for children with DS. It is committed to the welfare of children with DS, its main focus being the education of these children below 6 years old. Each centre provides the Early Intervention Program covers gross and fine motor skills, social development, academic skills, cognitive skills, self-help skills and speech therapy.
- 2) **Kiwanis Disability Information and Support Centre, KDISF** - It serves as a one-stop centre to assist people in looking for disability information and resources. It is a very useful website to provide up-to-date information on any aspects of disability, easy access to disability resources and services available in Malaysia, connecting all organizations, groups, professionals and service providers involved with disabilities in Malaysia, to form an online disability database and community accessible 24 hours a day, to provide parents with disability information, etc.



- 3) **Down Syndrome Association of Malaysia** – Mission to integrate, collaborate and build partnerships with the government, corporations and general public to generate awareness and compassion towards the Down Syndrome community; to provide services, resources and assistance to all state affiliated associations; to coordinate activities with DSAs at state level; to increase public awareness on PWDS; getting in touch with PWDS and their parents across the nation; organize seminar, workshops and discussions with members and affiliated DSAs; coordinate various activities locally and internationally, etc.
- 4) **DSA in other states** – Johor, Kedah, Penang, Terengganu, Negeri Sembilan, and Sarawak are providing services to increase awareness of the public towards DS and to provide training for children with DS, and their parents.
- 5) **Other NGO** – There are other NGO which render assistance and services to PWDS whenever necessary as part of their commitment to social service for PWD. Among these are Malaysian Care, Cheshire Home, CareHeart, *Taman Sinar Harapan* and many religious organizations.

#### 4.6. Gaps between policies and implementation

Laws and policies enshrined the rights for PWD but there are still many gaps between policies and real setting (M. Rezaul, 2015) which draw criticisms from PWD and people who are concerned with the welfare of PWD [33]. There have been many meetings and discussions with government authorities but opinions of PWD or their representatives on issues affecting their welfare and livelihood are often excluded. For the intellectually challenged like PWDS, they do not have the ability to exercise their civil, political, social, economic and cultural rights on equal basis with others; therefore they are socially excluded and left out of the development main stream. The advocacy and champions on disability issue and rights of PWDS in Malaysia is still not strong to push for better treatment.

Besides the government action and support, NGO play an extremely important role in practicing those policies [34]. In Malaysia, there is no organized intervention or training system from government for infant and toddler with DS. Families or parents rely more on NGO and private therapists. Kindergartens available for children with DS are limited and they do not meet the requirement, so most parents still send their DS children to the NGO. For the school children (6-19 years old), there is organized education system by government in Malaysia. Most individuals with DS at this age could be placed at government schools where teachers are required to write and implement Individual Education Plan (IEP) for each student. Almost all students with DS in Malaysia do not enter the post-secondary school after 19 years old to experience vocational skills training as they are not able to sit for public examinations at upper secondary school due to the lack of intellectual ability. Currently the adulthood of PWDS is a huge challenge and stressful for this population and family if they could not get the vocational training for future employment. When they face the difficulties in access to employment and education, their life quality and wellness will be jeopardized in future. The gaps between policies and practice remain a significant problem for PWDS.

The MOE is aiming to achieve 30% enrolment of students with SEN in the mainstream classes by 2015. At the moment only less than 10% of students with SEN are in the inclusive classes. Situation may be improved should students with DS were either mainstreamed or put in inclusive education or at least having effective learning experience with IEP carefully planned for them. However, most of these actions are either absent or not implemented effectively. The basic principles of writing IEP are not adhered to, many parents' voices were not heard or they are not being told or explained about IEP – its significance and parental role in its implementation. There was a lack of proper or effective documentation of students learning or assessment. Even though the hardware provided by MOE is sufficient and of quality, but they are not optimized for teaching both academic and vocational skills. Teachers' low expectations and negative perceptions on students with DS abilities in academic may inhibit the opportunities in learning. In addition, teacher's competencies in pedagogy seem to be a hindering factor in IE implementation. According to Bosi (2010), most of the Malaysia teachers were trained only to teach children placed in traditional classrooms and they had no experience in teaching children with special needs [35].

Some school authorities are found to be not cooperative and dehumanizing in some instances. There was a case of school management deprived the opportunity of a high functioning student from joining the mainstream in the pretext that the student will bring down the performance of the school [35]. Students with severe physical and mental disabilities are usually not recommended by medical personnel for placement into government-run school but are recommended to enrol into Community-Based Rehabilitation centre or they may choose other educational institutions managed by NGO. Due to various constraints, some students with disabilities are kept at home and they miss out the educational experiences in school setting. Obviously the law does not protect the rights to education for all PWDS.

Predicaments faced by PWDS maybe the result of lax enforcement of Persons with Disabilities Act 2008. Disabled people have been complaining that the PWD Act 2008 is purely an administrative act as there are no punitive measures for non-compliance or acts of discrimination. This Act acknowledges the rights of disabled people and moves away from a welfare-based concept to the rights-based concept. There is *no provision for penalties* because it is not the purpose of this Act to punish disabled people. However, the penalties for parties not in compliance to this Act will be stated in other Acts, regulations and by-laws.

When law enforcement is lax, various policies and initiatives are not properly implemented. Khoo et. al (2012) pointed out the 1% of civil service positions to PWD are merely policy statement without running its annual course [36]. Research has also shown that there are specific issues encountered by PWD in employment causing low employment rate among this population. Melissa and See (2011) reported that the increasing demand for academic and job-related skills may make it more difficult for PWD to find jobs [37]. Factors which further inhibit this situation include inaccessible transportation, inaccessible buildings, and negative attitudes by employees, low self-esteem and overprotective families. Research by Tiun and Khoo (2013) showed that the highest percentage among the unemployed were people with learning disabilities which include PWDS, at 53.5% [38]. A high percentage of them have low educational qualifications and are unable to be independent, thus job opportunities for this group are mainly with NGO and many may not be able to find any jobs at all. Self-employment is an option but many of them are just helping their parents to run small scale business or just stay at home with their siblings. Heron and Murray (2003) found that employers often exclude PWD from their list of employees as they are regarded as unsuitable for employment [39].

## 5. RECOMMENDATION AND CONCLUSION

PWDS could be considered as one of the most vulnerable of the minority groups in the Malaysian population. With their inadequacies in developmental aspects and learning as well as unstable health conditions, various effective measures involving government agencies, public sector, NGO and society in general, should be planned and implemented or to update and revise those existing ones. Organizations or schools which provide educational services should teach PWDS in academic subjects for them to acquire basic knowledge and communication skills. PWDS should be taught vocational skills to prepare them for employment and to be self reliant. Counselling, cognitive and behaviour therapies should be available to help PWDS manage their behaviour in an appropriate manner. Families with PWDS should be supported so that they could provide conducive environment for PWDS. Society at large should recognize the value and contribution of PWDS to our communities. Quality educational program, stimulating home environment, good health care and positive support from family, friends and the community are all important factors to enable PWDS to develop full potential and lead fulfilling lives.

Research should be carried out to focus on the issue of wellness among PWDS and their families to gain better understanding of helping and hindering factors for PWDS to live a meaningful life.

In summary, a holistic approach that involves various stakeholders – PWDS, parents, siblings, government agencies, educators, employers, counsellors, NGO, job coaches and media, is needed to provide appropriate and effective measure to enhance knowledge, skills and competencies of PWDS.

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