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# Current Status and Issues of Healthcare Policies for Persons with Developmental Disorders in Southeast Asia

Edited by

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## List of Abbreviations and Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
AMS	ASEAN Member States
ASEAN	Association of South-East Asian Nations
ASD	Autism Spectrum Disorder
ASP	Autism Society Philippines
CBR	Community-based Rehabilitation
CCIHP	Centre for Creative Initiatives in Health and Population
CRPD	Convention on the Rights of Persons with Disabilities
CSWDO	city or municipal social welfare and development office
DOH	Department of Health of the Philippines
ECCD	Early Childhood Care and Development Council
ICT	information communication and technology
IDD Net	Indonesia Developmental Disorders Network
MEXT	Ministry of Education, Culture, Sports, Science and Technology of Japan
MHLW	Ministry of Health, Labour and Welfare of Japan
MOET	Ministry of Education and Training of Viet Nam
MOH	Ministry of Health of Viet Nam
MOLISA	Ministry of Labour, Invalids and Social Affairs of Viet Nam
NCDA	National Council of Disability Affairs of the Philippines
NGO	non-governmental organisation
PDL	person with deprived liberty
PIN	Project Inclusion Network

PRPD	Partnership on the Rights of Persons with Disabilities
PWDs	persons/people with disabilities
RA	Republic Act
SDM	Supported Decision-Making
SPED	special education
UN	United Nations
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VAN	Vietnam Autism Network
VDS	National Survey on Persons with Disabilities (Viet Nam)
WHO	World Health Organization

# Chapter 1

## Introduction

### 1.1 Overview of the project

Persons with developmental disorders and their parents often encounter numerous and overwhelming challenges in caring for themselves, their children, and other family members. The impact is magnified if more than one family member has a developmental disorder. These challenges often result in adverse effects on their lives, including a lower quality of life, a sense of isolation, and lack of knowledge in care planning.

There is a lack of understanding about healthcare policies, and limited access to consistent and standardised training and other forms of support in Southeast Asia. Persons with developmental disorders and their parents, along with government, non-governmental organisations (NGOs), universities, business, and other stakeholders can greatly benefit from useful and relevant research for both individuals and groups. The outcomes of this research project will aid those people affected in the ASEAN community in developing new perspectives and approaches to coping with their challenges. Through the process, they will gain knowledge of various policies and acquire new life skills that will benefit them, including their children, in the long term.

The research on 'Current Status and Issues of Healthcare Policies for Persons with Developmental Disorders in Southeast Asia (Healthcare Policies)' is a pioneering project in the ASEAN region in consultation with the partners in Japan. The healthcare policy research was conducted simultaneously with a guidebook titled 'Development of Parent Training, Mentoring, and Group Coaching Guidelines to Enhance the Quality of Life of Parents of Persons with Developmental Disorders in Southeast Asia.

With the goal to maximise the synergy between analysis on healthcare policies and the development of a guidebook, these projects offer the ASEAN community a means to assist everyone, particularly those with developmental disorders and their parents, to overcome challenges and empower themselves for the long term in our society. An additional target audience for this project includes government agencies, organisations representing persons with developmental disorders and their families, and researchers involved in developmental disorder-related policies and practices in Indonesia, the Philippines, and Viet Nam. Both projects started in December 2021. Overall, the essence of the research, as found in the comprehensive set of research outcomes, will pave the way for persons with developmental disorders and their parents to cope with challenges and, in the process, enhance their quality of life. The guidebook and the research will also be beneficial for other stakeholders, such as government agencies, advocacy groups, and researchers in developmental disorder, as these documents can provide as references of analysis situations on developmental disorders in ASEAN countries.

In brief, the activities being implemented are participatory action research focused, whereby persons with developmental disorders and their parents committed to improving their lives for the better, joined research activities to learn how to adjust their behaviour and perceptions. Simultaneously, they have had the opportunity to exchange valuable information with others and learn effective ways to interact with other stakeholders. The analysis on the healthcare policies for persons with developmental disorders and the guidebook based on those practiced in Japan could ensure that more people in the ASEAN region will have access to health services.

The research activities are expected to influence the future direction of how this issue is handled and researched in the ASEAN region. Studies on policy analysis for persons with developmental disorders in the Asia-Pacific region are few. The availability of policies related to developmental disorders that are not widely recognised in the ASEAN region, such as Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), and learning disabilities (LD), is recent and limited in scope. As a result, they have not been analysed for their accessibility, efficacy, and impact. Therefore, an analysis of situation related to developmental disorders in the ASEAN region is needed to obtain a comprehensive understanding of the status of this topic.

## **1.2 Methodology**

During the first 3 months of this research project (December 2021–February 2022), a research methodology kit was developed. This included constructing a questionnaire and an interview guideline. It includes close-ended questions for Google forms used in questionnaires and open-ended questions for guideline-based semi-structured interviews. Both instruments (questionnaire and guideline questions) were distributed to be filled out and answered by the experts. For the project, 34 experts comprising representatives from government agencies, civil society/NGOs, and academic scholars in developmental disorders were invited to a series of discussion sessions. The list of experts and the research methodology kit (questionnaire and interview guideline) are attached in the Appendix.

Items included in the questions list include:

- Information on the current situation of people with developmental disorders and health policies aspects
- Categories of support for people with developmental disorders (e.g. early detection and assessment, schools and education programs, work and community life support, family support, advocacy, disaster mitigation, and public administration services)
- Efforts to enhance the life of people with developmental disorders (e.g. human resources and research development)

Academic publications as well as policy and research reports about developmental disorders in ASEAN countries were used as references to develop the research methodology kit. During the kit development process, the researchers conducted several discussions with the experts (scholars and organisations related with developmental disorders in three countries in the pilot study – the Philippines, Indonesia, and Viet Nam – and valuable inputs from Nozominosono (The Independent Administrative Institution, The National Center for Persons with Severe Intellectual Disabilities) were received. From these discussion sessions, several key issues related with health support and developmental disorders in ASEAN countries were developed. These key issues include (i) health access and support; (ii) inclusive and special needs education; (iii) employment support; (iv) advocacy and activism; (v) other support such as community life, group home, judicial procedure, disaster mitigation, and crisis support; and (vi) research on developmental disorder. These key issues are discussed in the chapters of this report.

Throughout the first and second years of the project, data collection and literature review were conducted concurrently with the interviews, missions, and training programs. Data gathering was in the form of presentations and discussions based on interview questionnaires with identified leaders with disabilities, parents, experts, and other stakeholders from the perspective of developmental disorder. Information gathering was also held consecutively with various sessions, whereby research partners share their firsthand and practical experiences, which could consist of suggestions and recommendations on how to enhance their quality of life for persons with developmental disorders as the key research deliverable.

The interview session is specifically intended to provide an in-depth discussion about the situation of people with developmental disorders from the key resources' point of view (Chapters 3 and 4). The information from the interview session, along with the questionnaire, was used for case studies in the report from the three pilot countries: Indonesia, the Philippines, and Viet Nam.

### **1.2.1 Ethical issues**

Before questionnaires were distributed and interview sessions conducted, an information sheet and consent form were sent to the informants. This includes the information about the research project and the methods, data confidentiality, and security of personal information for the project and the publication of research results. The ethics committee at Nozominosono had approved the research project.

### **1.3 The structure of the report**

This report is divided into six parts: Chapter 2 comprises literature reviews on concepts related to developmental disorders, including prevalence data, legal and policy frameworks, and emerging issues in the ASEAN region. Chapter 3 provides a situational

analysis of persons with developmental disorders in Indonesia, the Philippines, and Viet Nam. Chapter 4 explores important issues from the perspective of persons with developmental disabilities and their families. Chapter 5 compares policies between Indonesia, the Philippines, Viet Nam, and Japan. Chapter 6 concludes and presents the implications of the research project, providing important recommendations for future research and an action plan.

## Chapter 2

# Developmental Disorders in ASEAN: Trends and Challenges

### 2.1 Definition and Scope of Developmental Disorders

Developmental disorders/disabilities are 'a group of chronic, lifelong disabilities characterised by physical and/or mental impairment which manifested before the individual attains age 22 and result in substantial functional limitations in day-to-day activities such as self-care, communication, learning, mobility, independent living, and self-direction' (American Association on Intellectual and Developmental Disabilities, 2020). This condition commonly presents during childhood and is likely to continue indefinitely therefore, it can affect a person's independent participation in society (Smith and Shapiro, 2023; Mardiyanti, Cuthbertson, and Jewell, 2020).

Previous studies refer to some common categories of developmental disorders, including Attention Deficit Hyperactivity Disorder (ADHD), ASDs, learning disabilities, behavioral and emotional disorders, communication disorders, cerebral palsy, and Down Syndrome (Patel et al., 2010, in Mardiyanti et al., 2020).

In this report, we use the term 'developmental disorders' to put more specific scope of the definition we want to explore further. The term 'developmental disorder' used in this research project refers to the United Nations (UN) General Assembly (includes ASD, developmental disorders and associated disabilities) and Act on Support for Persons with Developmental Disorders in Japan (includes Autism, Asperger Syndrome and other pervasive developmental disorders, learning disabilities, Attention Deficit Hyperactivity Disorders/ADHD, etc.). The terms 'developmental disorders' and 'developmental disabilities' will be used interchangeably in this report, as some official documents and data reports we used as references also use the term developmental disabilities. More detailed explanations on the scope and category of developmental disorders used in this report can be found on Box 1.

#### **Box 1: The Scope and Category of Developmental Disorders**

The category of developmental disorders discussed in this report refers to Autism Spectrum Disorders (ASDs), Attention Deficit Hyperactivity Disorder (ADHD), and learning disabilities. This is due to case studies in some ASEAN countries that refer to these categories. Below are the specific definitions of the categories discussed in this report:

- ADHD is a neurodevelopmental disorder characterised by inattention and disorganisation, with or without hyperactivity-impulsivity, causing impairment of functioning (Vierhile et al., 2017).
- ASD or Autism refers to a group of neurodevelopmental disorders as pervasive

developmental disorders. Autism is characterised by severe impairment in reciprocal social interactions and communication skills, as well as the presence of restricted and stereotypical behaviors (Faras, Ateeqi, and Tidmarsh, 2010).

Learning disorders refer to difficulties in one or more areas of learning and can also be present with emotional or behavioral disorders, such as ADHD or anxiety. Some examples of learning disorders include Dyslexia (difficulty with reading), Dyscalculia (difficulty with math), and Dysgraphia (difficulty with writing) (Sulkes, 2024).

Source: Compiled by authors (2023).

Developmental disorders are long-term conditions that persist throughout life, affecting not only the individual but also their family. Currently, the life expectancy of most persons with developmental disabilities is advancing towards the life expectancy of the general population (Kripke, 2018). The improvement of medical practises, the advancement of rights for persons with disabilities (PWDs) and the innovation of assistive supporting tools are part of contributing aspects to improve the life expectancies of PWDs. Therefore, children and adults with developmental disorders require significant support from their families (Scott et al., 2016) including a full life care support. They also need increased access to healthcare, early childhood care and development services, and education. Measuring the prevalence of developmental disorders in the population is crucial to determining whether the available services and interventions are adequate. In the following section, the estimated number and prevalence of persons with developmental disorders in ASEAN Member States (AMS) will be discussed further.

## **2.2 The estimated number and prevalence of developmental disorders in ASEAN**

About one in every six people in Asia and the Pacific (about 690 million people) live with a disability (Crosta and Sanders, 2021). This includes people with physical disabilities (blind or with low vision, deaf, or hard-of-hearing), learning disabilities, cognitive/developmental disabilities, psychosocial disabilities, and multiple disabilities (Crosta and Sanders, 2021).

While specific data on the prevalence of developmental disorders in ASEAN is absent, it is essential to update prevalence estimates. This is necessary to raise awareness and inform policy initiatives, as well as increase service planning, resource allocation, and research priorities (Olusanya et al., 2023). About 240 million children globally have developmental disabilities based on parent-reported functional difficulties (Olusanya et al., 2023).

Based on previous studies, South Asia is where children and adolescents with mental and developmental disorders are mostly found. This is due to the increasing numbers of population in this region and the decreasing numbers of infants and young children's



mortality (Murray et al., 2007 Patel et al., 2016). Table 2.1 shows the estimated prevalence of PWDs and developmental disabilities in the AMS. The data shown are various due to the differences in data collection methods, as it is compiled from various sources of government statistics and organisations related to developmental disabilities.

**Table 2.1: Estimated Number and Prevalence Data of Persons with Developmental Disorders in ASEAN Countries**

No.	Countries	Estimated Number of Persons with Disabilities (PWDs)	Estimated Number of Persons with Developmental Disorders
1	Brunei Darussalam	7,038 (1.6% of the total population)	1,858 (children and youth with autism)
2	Cambodia	4.7% of the total population (per 2016)	More than 20,000 persons with autism, ADHD, intellectual disabilities, Down Syndrome (Cambodia Autism Network, 2023 <sup>1</sup> )
3	Indonesia	26 million (9.7% of the total population)	2,729 (persons with autism)
4	Lao PDR	160,881 (2.8% of the total population)	No specific data, but from total number of PWD, there are persons with self-care disability (1.1%) and persons with speech or communication disability (0.9%)
5	Malaysia	637,537 (1.9% of the total population, per 31 January 2023)	21,287 (persons with autism in 2018) 9,063 (children in school age with learning disabilities in 2018)
6	Myanmar	12.8% of the total population or 6.5 million (Myanmar Ministry of Labour, Immigration and Population, 2020)	No specific data found, but in 2010 National Report on Disability stated 8.1% from disability population has intellectual disabilities (Ware and Schuelka, 2019; Myanmar Ministry of Labour, Immigration and Population, 2020)
7	Philippines	12% of the total population (age 15 and older) with severe disabilities 23% of the total population (age 15 and older) with mild disabilities (Lisa, 2019 )	24,657 (learning disabilities) 0.32% (of school age with intellectual and developmental disabilities)

<sup>1</sup> Data compiled from interview with Chan Sarin, chair of Cambodia Autism Network, in October 2023.

8	Singapore	2.1% of student population 3.4% of resident population (18–34 years) 13.3% of resident population (50 years above)	One in 150 children has autism 4,400 children were diagnosed with developmental issues (per 2014)
9	Thailand	3.7 million (5.5% of the total population)	12,643 (persons with autism)
10	Viet Nam	6.2 million (7.06% of the total population)	200,000 (persons with autism recorded data per 2018)

Sources: Compiled by authors (2023).

From Table 2.1, there is an absence of reliable data of developmental disabilities in ASEAN countries, which may indicate that PWDs are marginalised from mainstream development policies in many countries (Wardana and Dewi, 2017). This may partly be caused by the unclear definition of developmental disorder, as each country has different categorisation of developmental disorder. Consequently, this lack of data in developmental disability prevalence can lead to several challenges faced by disabled people, including inadequate policies and standards, negative attitudes related to stigma and discrimination, insufficient services and funding, as well as inadequate funding and absence of their participation in political and public life.

### 2.3 Law and Policy Frameworks on Developmental Disorders

The rights and inclusion of people living with a disability are a critical issue for all AMS. Therefore, to uphold the rights and ensure the provision of health services for persons with developmental disorders, national and local policies can align with international regulatory frameworks that emphasise the need to ensure the provision of health services for PWDs. Below is a list of the most comprehensive international and regional regulatory frameworks on PWDs, including persons with developmental disorders in ASEAN:

- **The Convention on the Rights of Persons with Disabilities (CRPD)** is the reference for the fundamental regulatory framework and entered into force in 2008. All 10 AMS have signed and ratified the CRPD, which legally protects the human rights of all PWDs to participate in society on an equal basis with others (UNESCAP, 2022).
- **The UN Partnership on the Rights of Persons with Disabilities (PRPD) Strategic Operational Framework 2020–2025.** This framework was published by the UNPRPD to support the implementation of the CRPD and address key developments in today's disability inclusion landscape (UNPRPD, 2022).
- **The UN 2030 Agenda for Sustainable Development** aims to include PWDs (and 'persons in vulnerable situations') to ensure that 'no one is left behind' in

achieving the Sustainable Development Goals (SDGs). This is linked to goal 10: 'Ensure equal opportunity and reduce inequalities of outcome, including by eliminating discriminatory laws, policies, and practices and promoting appropriate legislation, policies, and action in this regard'<sup>2</sup>. The UN Disability and Development Report is a flagship report that reviews data, policies, and programs and identifies best practices. It uses this evidence to outline recommended actions to promote the realisation of the SDGs for PWDs (UN, 2018).

- **The Incheon Strategy** is a framework by UNESCAP for the Asia-Pacific region to promote disability inclusive development and to monitor the progress of implementing the United Nations Convention of the Rights of Persons with Disabilities in the region. It includes 10 goals covering social, political, and economic participation and inclusion; accessibility; education; gender equality; disaster risk reduction; data on disabilities; and regional cooperation (Jamir Singh, 2022; Thoresen et al., 2017).
- **The ASEAN Enabling Masterplan 2025** was proposed by the ASEAN Secretariat to complement and concretise the ASEAN Community Vision 2025 in mainstreaming the rights of PWDs across all three pillars of the ASEAN Community and foster all 10 AMS' commitments to disability inclusion, especially regarding specific CRPD commitments (Crosta and Sanders, 2021).

It is necessary to ensure the full participation of PWDs and organisations of PWDs in creating health policies and regulations, to mainstream PWDs' health issues (ASEC, 2023). The shift in perspectives from medical model or paradigm to human rights-based approach in viewing disability also means that PWDs have the right to accept or reject through 'informed consent' (ASEC, 2023).

## 2.4 Challenges and Emerging Issues in Developmental Disorders

Developmental disorders during childhood are an emerging challenge to healthcare systems globally (Patel et al., 2016). This is due to two main factors: the increasing populations of children and adolescents in the low- and middle-income countries, and the fact that many adult mental and developmental disorders occur in childhood and adolescence (Patel, et al., 2016).

Majority of existing studies on developmental disabilities have been conducted in English-speaking high-income countries (Tomlinson et al., 2014). There is a lack of references on health research that is insensitive to issues of gender, culture, and ethnicity (Tomlinson et al., 2014).

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<sup>2</sup> [https://sdgs.un.org/goals/goal10#targets\\_and\\_indicators](https://sdgs.un.org/goals/goal10#targets_and_indicators).

As discussed in the previous section on the prevalence of developmental disorders, the absence of reliable data on disabilities, particularly developmental disabilities, indicates the marginalisation of PWDs from mainstream development policies in many countries (Wardana & Dewi, 2017). The lack of reliable data on disabilities will cause challenges faced by disabled people, includes inadequate policies and standards, negative attitudes related to stigma and discrimination, lack of provision of services, inadequate funding, lack of accessibility, and lack of consultation and involvement (Wardana and Dewi, 2017).

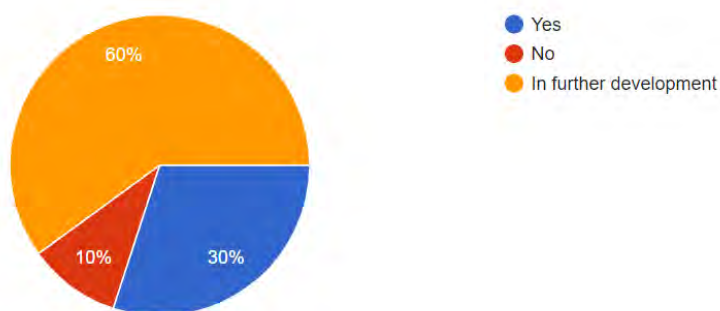
During childhood, children with developmental disabilities possess a higher risk for developing behaviour problems, lower verbal and nonverbal communication skills – as well as experiencing feeding and nutritional problems – compared to those without developmental disabilities (Widyawati et al., 2023). Because of these disadvantages, children with developmental disabilities will more likely have a lower quality of life than those with typical developmental (Ncube et al., 2018; Widyawati et al., 2023). One of the most promising ways to improve the quality of life for children with developmental disabilities and their families is early detection, in order to receive proper intervention (Chunswan, Hansakunachai, and Pornsamrit, 2016).

#### *Availability of health programs for developmental disorders*

One basis for identifying developmental disorders in children is through developmental surveillance or monitoring, and by conducting developmental screening programs (Mardiyanti et al., 2020). These programs are targeted towards young children between birth and preschool age, and generally provided by general practitioners or pediatricians through regular health assessments and supervisions (Mardiyanti et al., 2020).

Providing early identification and intervention programmes in developing countries can be a challenge, specifically in remote and rural areas where poverty rates remain high and lack of expertise in healthcare systems is still a major problem. However, most AMS can provide early detection and intervention programmes for children (below 6 years old) (Figures 2.1, 2.2, and Table 2.2), despite the services in some countries still in further development. The figures show the responses from the questionnaires on the provision of early detection and child developmental support, while the table describes the examples of programmes for children, teens, and adults with developmental disorders provided by government agencies, NGOs and private institutions in ASEAN countries. Data in the following figures and table were collected from informants in this project, as explained in chapter 1.

Figure 2.1: Access to Early Detection and Screening for Developmental Disorders



Source: Questionnaire data (2023).

Figure 2.2: Provision of Early Child Developmental Support<sup>a</sup> for Parents and Caregivers



<sup>a</sup> Such as daycare and parent trainings

Source: Questionnaire data (2023).

Table 2.2: Provision of Health-related Programmes for Persons with Developmental Disorders

Countries	Provided by Government Agencies	Provided by Non-governmental organisations (NGOs) and Other Private Institutions	Example of Programmes
Brunei Darussalam	The Ministry of Health via Child Development Centre and the Pediatrics Department	- SMARTER Brunei (for autism) - Pusat Ehsan Al-Ameerah Al-Hajjah - Maryam Learning ladders Society	- Early detection of children with autism - Intervention services for other disabling conditions
Cambodia	- The Ministry of Health - The Ministry of Social Affairs, Veterans and Youth Rehabilitation - Centre for Child and Adolescent Mental	- Hand of Hope Community - Karona Battambang - Komar Pikar - Safe Haven - Grace House Community Centre - CIF (ABLE Project)	- Early intervention programmes - Case management and personalised support plan for children

	Health (Moeun, et al., 2022)		
Indonesia	<ul style="list-style-type: none"> <li>- The Ministry of Health</li> <li>- The Ministry of Women Empowerment and Child Protection</li> </ul>	<ul style="list-style-type: none"> <li>- Autism Indonesia Foundation</li> <li>- Masyarakat Peduli Autisme Indonesia Foundation</li> </ul>	<ul style="list-style-type: none"> <li>- Several programmes including stimulation, detection, and early intervention for growth and development (for children under age 5) to detect early growth and development disorders</li> <li>- Assessment for emotional and behavioural problems (SDQ for children and teen aged 4–18 years old; SRQ for adult aged 20 years above)</li> </ul>
Lao PDR	Limited involvement of the government	<ul style="list-style-type: none"> <li>- Association for Autism Laos through centres in few areas (Vientiane Autism Centre and Pakse Autism Centre)</li> </ul>	<ul style="list-style-type: none"> <li>- Early intervention programmes</li> <li>- Knowledge and awareness programmes</li> </ul>
Malaysia	Department of Social Welfare	National Autism Society of Malaysia	<ul style="list-style-type: none"> <li>- Early intervention programmes for children</li> <li>- Training and development programmes for teen and adult</li> </ul>
Myanmar	Department of Social Welfare	Myanmar Autism Association	<ul style="list-style-type: none"> <li>- Early childhood intervention service (aged 0–5 years) through Early Childhood Care and Development (ECCD)</li> </ul>
Philippines	<ul style="list-style-type: none"> <li>Department of Health (DOH) via the ECCD Council</li> <li>National Council of Disability Affairs (NCDA)</li> </ul>	<ul style="list-style-type: none"> <li>- Autism Society of the Philippines (ASP)</li> <li>- ADHD Society of the Philippines</li> <li>- Philippine Dyslexia Foundation</li> <li>- NORFIL Foundation</li> </ul>	<ul style="list-style-type: none"> <li>- Early intervention services</li> <li>- Training and workshops for children, teen, and adults</li> </ul>
Singapore	The Government via Early Intervention programmes	<ul style="list-style-type: none"> <li>- Enabling SG</li> <li>- Autism Association Singapore</li> </ul>	<ul style="list-style-type: none"> <li>- Early Intervention Programme for Infants and Children</li> <li>- Pilot Private Intervention Providers</li> <li>- Government-funded Integrated Child Care Programme in preschools</li> </ul>
Thailand	Department of Mental Health and Special Education Centre	<ul style="list-style-type: none"> <li>- Autism Awareness Thailand</li> <li>- Autistic Thai Foundation</li> <li>- The Rainbow Room</li> </ul>	<ul style="list-style-type: none"> <li>- Early intervention services and Rehabilitation Awareness Training Center</li> <li>- Life skills training for</li> </ul>

		Foundation	adolescents and parents
Viet Nam	Available by government agencies in some major cities (early intervention program and autism services)	- Vietnam Autism Network (VAN) - Centre for Creative Initiatives in Health and Population (CCIHP)	- Early detection and intervention - Orthopaedical surgery and provision of assistance to PWDs

Sources: Compiled by authors (2023).

Table 2.2 shows that most ASEAN countries have health-related programmes for children provided by the government and NGOs. Some countries, such as Indonesia, Malaysia, the Philippines, and Singapore, have developed trainings and programmes for teens and adults with developmental disorders.

Based on the interview data with our key informants, most of the social support and services provided by the state, NGOs, and private institutions for persons with developmental disorders are available in cities or urban areas. A previous study on parents of autistic children living in Asia, especially in rural areas, reported their challenges in obtaining proper diagnosis and treatment, as they had to travel to main cities or even overseas due to a lack of local resources (Shorey et al., 2020). Parents and caregivers in ASEAN state countries also have the same experience. For example, in Cambodia, service provision to persons with developmental disabilities, including autism, is still limited to urban areas (Pov, 2021). This also applies to education services, where only four provinces in Cambodia (in urban areas) amongst 25 provinces can provide access to education for autistic children, while those with autism are accessible (Panyasirimongkol et al., 2020a).

Despite some functional limitations, people with developmental disorders can have a good quality of life in their homes and communities. This can be obtained if they receive adequate support in medical care, as well as support for their decision-making process. Families and caregivers also need to obtain the necessary information related to skills and resources to support persons with developmental disorders to have a good quality of life. Accommodations such as disability services, housing modifications, and assistive technology tools are also needed to support the full inclusion of people with developmental disorders (Kripke, 2018).

### **Box 2: Healthcare and Well-being for Persons with Developmental Disorders**

The World Health Organization defines health as ‘...a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’. This definition of health is often being criticised as there is a need to address issues beyond the traditional medical model – to move beyond the emphasis on the reduction or elimination of deficits or deficiencies, and to promote more ‘physical, mental, and social well-being’ (Lollar and Phelps, 2016). This is critical for the health needs of children with developmental disorder because they are the most vulnerable groups

bearing the risks of secondary conditions (Lollar and Phelps, 2016).

Health is an ingrained component and a determinant of well-being (UN, 2018). Therefore, the ultimate goal of healthcare for persons with developmental disorders is to improve their well-being, function, and participation in family and community (Kripke, 2018). People with developmental disorders have a significantly higher risk of chronic health conditions (e.g. diabetes or mental health conditions) compared to the general population (Dahm et al., 2019). Previous studies show that people with developmental disorders still have inequitable access to healthcare. Specific policies, innovative delivery models, and targeted outreach efforts are necessary to develop in order to provide more access to healthcare services for people with developmental disorders and their families (Cheak-Zamora and Thullen, 2017).

### *Provision of inclusive and special needs education*

People with disability have a right to education without discrimination (Article 24, CRPD). On that account, all people with developmental disabilities, including children and youth, are entitled to receive appropriate public education. In ASEAN countries, there are two different paths of schools, namely, inclusive education and special needs education (see Table 2.3). Inclusive education is a set of educational services that includes all children, including children with disabilities, in the same learning environment. Meanwhile, special needs education or special education refers to 'separate schools, classes, or instruction specifically designed for students categorised as having special educational needs' (UNESCO, 2017).

**Table 2.3: Inclusive and Special Needs Education in ASEAN Countries**

<b>Countries</b>	<b>Inclusive Education</b>	<b>Special Needs Education</b>
Brunei Darussalam	Yes, the Inclusive Education Policy provides mainstream classes with the support of special education needs assistance teachers.	Yes
Cambodia	Yes, the Policy on Inclusive Education provides special schools integrated with mainstream classes.	Yes, but remote areas do not have special needs schools or inclusive mainstream schools
Indonesia	Yes, per Regulation No. 70/2009 on Inclusive Education. There are 1,600 schools (or 11% of all schools) in Indonesia providing inclusive education from kindergarten to higher education (UNESCO, 2021)	Yes, through special education units or special schools ( <i>Sekolah Luar Biasa</i> )



Lao PDR	Yes, per the National Policy on Inclusive Education 2011–2015	Yes, providing separate schools for students with complex disabilities
Malaysia	Yes, the Inclusive Education Programme enables students with disability to join the mainstream classrooms.	Yes, special education schools for students with hearing, visual, learning and other disabilities
Myanmar	Yes, the National Education Strategic Plan helps students with disabilities transition towards inclusive education programmes.	Yes, providing resource schools
Philippines	Yes, developing a national inclusive education framework to include students with disabilities	Yes, the Special Education Act of 2019 institutionalises at least one special education centre in each school division.
Singapore	Yes, depends on the type and severity of disability, students with disabilities can enter mainstream schools and access the curriculum in inclusive settings.	Yes, in total, 19 special education schools across the country
Thailand	Yes, per the 2008 Education Act for Persons with Disabilities, the country transitions to fully including students with disabilities in education. Currently has 13,786 inclusive schools nationally.	Yes, including 43 special schools, 76 provincial special education centres
Viet Nam	Yes, various stages of inclusive education development were being supported in 20 provinces and cities (in 2019).	Yes, 107 specialised education facilities and 12 education centres were operating in the country (in 2019).

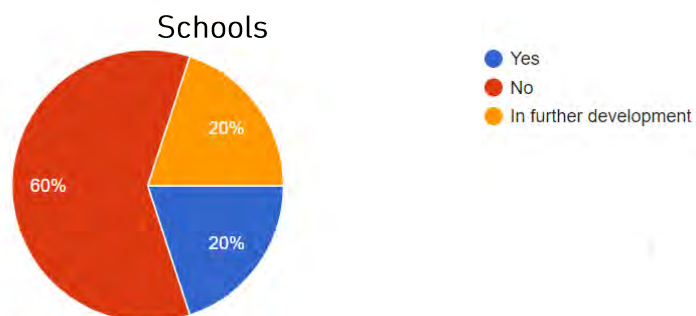
Source: ERIA (2022).

Inside the classroom, students with developmental disabilities, such as autism, ADHD, and learning disabilities, might need support in the form of an information and communication technology (ICT) system that understands the individual behaviours of children with developmental disabilities. For example, using digital content can enhance the learning process for students with learning difficulties, while assistive communication tools can provide support for students who have communication or verbal difficulties.

After-school support activities are also needed for students with developmental disabilities at the elementary, junior high, and high school levels. These extracurricular activities are a core part of the student experience, particularly for developing personal and social skills and their sense of belonging (Szücs and Harpur, 2023). Creating targeted programmes such as peer mentoring and awareness days can engage disabled students with their peers, while also developing more understanding about differences

(Szücs & Harpur, 2023). According to the survey (Figure 2.3), these after-school activities have not yet been adequately provided in most countries, as 60% of informants state about the inavailability of the programme in elementary, middle, and high schools.

**Figure 2.3: Availability of After-school (and Vacations) Programmes for Students with Developmental Disorders in Elementary, Middle, and High Schools**



Source: Questionnaire data (2023).

#### *Post-school age challenge: Employment support*

After graduation from school, PWDs generally face another great challenge: seeking for a job. PWDs are less likely to be employed than those without disabilities – and the case is even lower for women with disabilities (UN, 2018). Across eight geographical regions globally, lower rates of employment persistently affect PWDs.

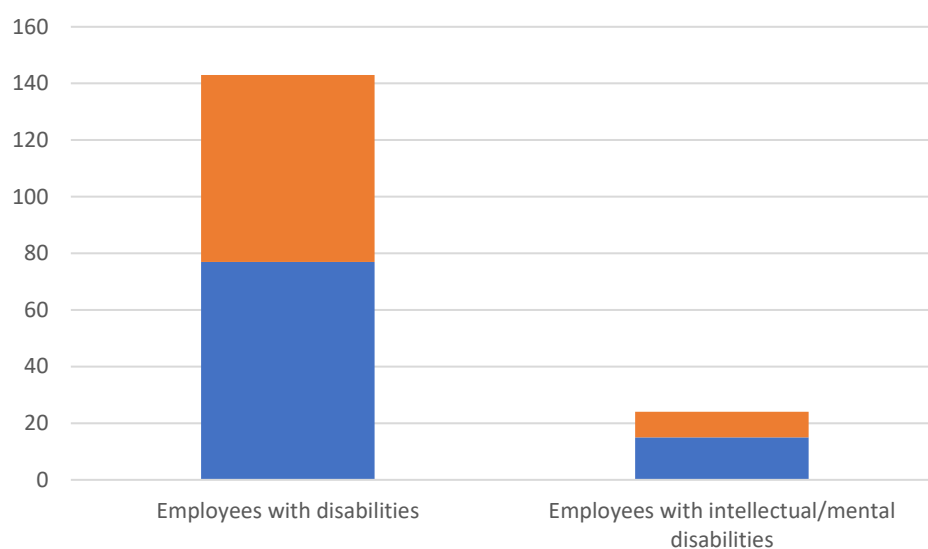
Several factors impact access to employment for PWDs. These factors include lower education levels, lack of accessible transportation, limited availability of accommodations in the workplace, as well as discrimination, stigma, and negative attitudes (UN, 2018). The lack of accessible transportation and disability-related services can also hinder PWDs from having full-time jobs. A previous study in 29 countries (2010) revealed a higher percentage of part-time employment amongst PWDs compared to those without disabilities (UN, 2018).

Based on the responses in our survey, several work supports are available for persons with developmental disorders in ASEAN countries, such as providing trainings for improving knowledge and skills to enter the workforce, as well as consultation support to find a job. Support is also given to employers to provide adaptation or settlement for employees with developmental disorders. Persons with developmental disorders can find employment through the job placement framework and with reasonable accommodation. However, in some countries, there is still a lack of support and reasonable accommodation for PWDs in general, including those with developmental disabilities.

Persons with mental and intellectual disabilities might have fewer opportunities to work in a company. In Indonesia, the number of employees with mental and intellectual

disabilities is very low compared to the overall population of employees with all categories of disabilities (Figure 2.4).

Figure 2.4: Comparison of Numbers of Employees with Disabilities



Source: APCD (2020).

In Cambodia, young adults with developmental disorders such as ASD work in offices, mostly doing basic administrative or documentation, cleaning and food preparing for guests (Asia-Pacific Development Center on Disability of Thailand, n.d.). There are vocational trainings for persons with developmental disabilities in ASEAN countries conducted by government agencies and non-governmental organisations, offering job placement opportunities after the completion of the training programmes. For example, in Singapore, SG Enable, a social service agency collaborates with other organisations or agencies to provide vocational assessment of needs and readiness for open employment, job placement, and job support services for PWDs. In the Philippines, the non-governmental organization Autism Society Philippines works with companies and universities to provide career placement opportunities and training programmes nationally.

Persons with developmental disorders must have training and information on how to access the support needed to find and maintain their jobs. Additional support services, such as transportation and accommodations, assistive technology, and accommodative facilities in the workplace should be available to them (NACBHDD, 2018). The policy and regulatory framework in the national employment scheme should encourage employers to recruit PWDs, such as providing tax deductions or credits for employees who retain their job for a particular term.

### Box 3: Developing a Supported Employment Model for Persons with Developmental Disorders

In 2023, a research team from MIND Institute UC Davis Health in California, United States, tested an employment model called Individualised Placement and Support (IPS). This model was used to support employment in other conditions but was not widely applied to support persons with developmental and intellectual disorders.

Marjorie Solomon, a professor in the UC Davis Health Department of Psychiatry and Behavioral Sciences who leads the research project, states that 'Having a job is one of the greatest sources of life satisfaction for most of us, as it provides a sense of purpose and an income, and increases social contacts and independence.' (Sharp, 2023). However, employment rates for autistic individuals and people with other developmental disorders are extremely low.

The IPS model applies several principles, including no exclusions for anyone who wants to work, a commitment to competitive integrated employment that applies an integrated environment of typical or non-disabled workers with similar benefits, and provides customised job targeting employee's preferences and skills (Sharp, 2023). Additional support was also provided, such as counselling and long-term job support, and other services such as housing and transportation.

Source: Sharp (2023).

### *Stigma and discrimination*

Persons with disabilities, including those with developmental disorders, are amongst the most marginalised in society. They face physical barriers (buildings, transportation, and other physical infrastructures that are inaccessible); communication and information barriers (for example, delivery of information without sign language and books that are unavailable in Braille); and attitudinal barriers (such as low expectation, stereotyping, and bullying), amongst others (UNICEF, n.d.).

These barriers were ingrained in stigma and discrimination, which indicate negative perceptions of disability related with ableism (UNICEF, n.d.). Ableism refers to bias, prejudice, and discrimination against PWDs; it is based on the idea that PWDs are less valuable than nondisabled people (Villines, 2021).

In ASEAN countries, stigma still surrounds autism and other developmental disabilities, which might be seen as 'invisible disability' that is not immediately apparent. Previous studies in Indonesia explored traditional beliefs and local values of parenting as some factors related to stigma. Children are expected to be the source of the family's pride as they could bring happiness and wealth. If the expectation is not met because of having disabilities, then the child will possibly be stigmatised (Riany, Cuskelly, and Meredith, 2016).

Cultural factors and lack of information about developmental disorders might lead parents and children with developmental disorders to face stigma – as it might be influenced by cultural beliefs or experience self-blame for their child's diagnosis (Ilias

et al., 2018). Families with children with developmental disorders need adequate support from society and the surrounding environment, so understanding and acceptance about developmental disabilities at the societal level are needed to reduce stigma and discrimination. Research on the impact of stigma highlights the persistence of negative associations between stigma and mental and physical health (UNICEF, n.d.). Greater exposure to discrimination might lead to poorer self-rated health.

Both stigma and discrimination are multifaceted and ubiquitous. These are encountered in the media, amongst communities, friends and families, at school, and in public places. Children with developmental disabilities risk internalising negative beliefs and attitudes about themselves due to stigma and discrimination (Whiteley, Kurtz, and Cash, 2016). A multifaceted approach is required to reduce stigma and discrimination, including designing interventions in multiple sociological levels, to address different audiences and multiple sociological levels, by combining communications, advocacy, and programmes (UNICEF, n.d.).

## Chapter 3

# Situation Analysis of Persons with Developmental Disorders in Southeast Asia

This chapter discusses data on the situation analysis of persons with developmental disorders in Southeast Asia. Indonesia, the Philippines, and Viet Nam will be highlighted as case studies in this research report.

### 3.1 Indonesia

#### *Data of persons with disabilities*

Based on the data from the 2019 Indonesia National Socio-Economic Survey (*Survei Sosial Ekonomi Nasional – SUSENAS*), the number of PWDs in Indonesia is 9.7% of the total population, or about 26 million people. In Indonesia, the definition of disability is derived from the CRPD's definition of PWDs: 'Those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others'.

Based on this definition, data on disability survey is largely based on these categories: physical, mental, and intellectual disabilities or sensory impairments. The SUSENAS divided disability categories: blindness, deafness, muteness, physical impairment, intellectual disabilities, or other multiple disabilities; and mental disability (psychiatric/psychological).

#### *Definition and prevalence of developmental disorders*

Despite the absence of a specific category of developmental disabilities in Indonesia's national survey, the latest data from the Indonesian Ministry of Women Empowerment and Child Protection indicates that the prevalence of children with developmental disabilities is around 3.6%–4% (Anak, 2019; Widyawati et al., 2023). Monitored data from 2010 shows that approximately 2% of children aged 0–14 years in Indonesia or 1.5 million children have a developmental disability (Irwanto et al., 2010).

Children with developmental disabilities face several disadvantages, including difficulties in accessing education, public services, health services, infrastructure, rehabilitation services, mobility restrictions, and lack of social support (Widyawati et al., 2023). These children are likely to experience negative attitudes from others, such as stigma and bullying (Cameron and Suarez, 2017; Riany, Cuskelly, and Meredith, 2016; Widyawati et al., 2023).

In Indonesia, the provision for early identification of developmental delays and intervention for children with developmental disabilities is not available uniformly,

particularly in rural and remote areas. Early identification of developmental delays and disabilities is essential to support the best stages of development in children. One of the main objectives of early identification programme is to ensure that children in need receive appropriate and timely intervention (Mardiyanti, Cuthbertson, and Jewell, 2020).

#### *Indonesia's legal system and disability-related policies*

The leading government agency that holds the role as the central ministry for disability administration is the Ministry of Social Affairs. Other departments, including the Ministry of Health, the Ministry of Education and Culture, and the Ministry of Labor, are involved in disability issues. In 2022, the Ministry of Social Affairs partnered with the Ministry of Home Affairs to develop an integrated national data collection system. Statistical and administrative data on disability are indispensable to policy planning (Priebe and Howell, 2014). As such, the national data collection system is considered an urgent issue, to follow up to the implementation of Law No. 8/2016 on Persons with Disabilities – which is mandated in Articles 117 to 121 concerning national data and the issuance of disability identity cards.

On 18 April 2016, Indonesia enacted the Law on Disabilities (Law No. 8/2016 on Persons with Disabilities) based on the UN Convention on the Rights for Persons with Disabilities that the Government of Indonesia ratified in 2011. This law has become the basis of all basic legal frameworks related to PWDs in Indonesia. The previous act on disability matters was Law No. 4 of 1997 concerning Persons with Disabilities, which was repealed upon entry into force of this Law (Tendy and Jahen, 2022).

The laws concerning rights for PWDs in Indonesia originates in the 1945 Constitution, which establishes the foundation of all the laws concerning PWDs and provides social assistance to poor PWDs (Priebe and Howell, 2014). The second amendment to Article 28 of the 1945 Constitution states that 'every citizen has the right to live, defend his/her life and existence, establish a family, and have access to the means to fulfill his/her basic needs, education, employment, health care, and social protection'.

In December 2021, the Indonesian National Disabilities Commission or Komisi Nasional Disabilitas was officially launched with seven members, including three PWDs. The national commission was newly established to fulfill the mandate of Law Number 8 in 2016 and was inaugurated by President Joko Widodo on 1 December 2021. The commission's role includes monitoring, evaluating, and advocating for the implementation of the respect, protection, and fulfilment of the rights of PWDs.

Table 3.1: Indonesian National Laws and Policies Related to Developmental Disorders

Indonesian Laws and Policy	Disability Specific Laws
<ul style="list-style-type: none"> <li>• Article 28 (Second Amendment) of the 1945 Constitution</li> <li>• Law No. 13 and 14 of 1992 (Access to Transportation)</li> <li>• Law No. 28 of 2002 (Buildings and Universal Design)</li> <li>• Article 1 in Law No. 16 of 1997 (Disability/Special Data)</li> <li>• Law No. 20 of 2003 (National Education System)</li> <li>• Law No. 4 of 1997 (Employment)</li> <li>• Law No. 40 of 2004 (National Social Security System)</li> </ul>	<ul style="list-style-type: none"> <li>• Law No. 8/2016 on Persons with Disabilities</li> <li>• Government Regulation No. 36 in 1980 on Social Welfare for the Disabled</li> <li>• Ministerial Decree No. KM-71 Year 1999 on Accessibility of PWDs</li> <li>• Circular Letter No. 380/G.06/MN, Year 2003, on Inclusive Education</li> </ul>

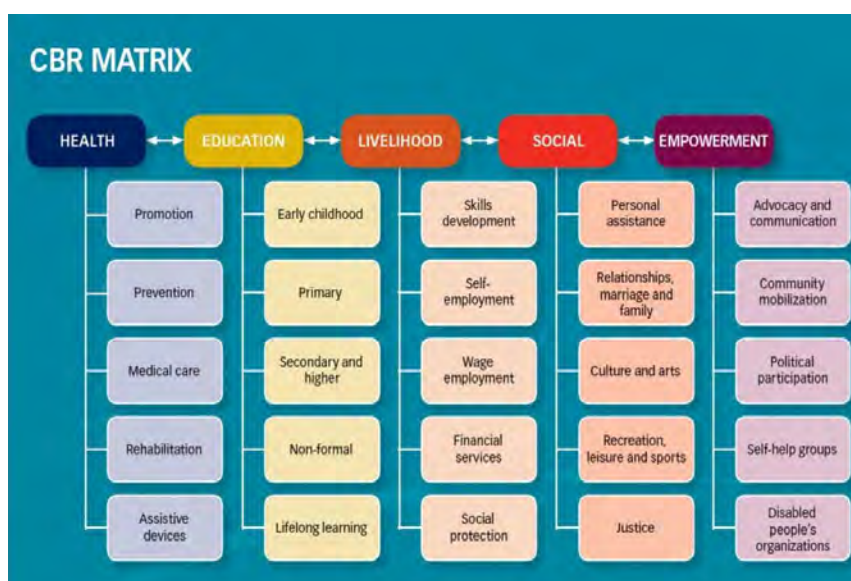
Source: Compiled by authors (2023).

*Access to healthcare and disability support and services for developmental disorders*

The Indonesian government has developed a framework strategy called Community-based Rehabilitation (CBR). This strategy aims to improve the quality of life of PWDs by working closely with them, their families, and stakeholders at the local, national, and international levels.

The CBR is closely related to disability-inclusive development, which actively seeks to ensure the full participation of PWDs as empowered self-advocates in all development processes. It also works to address the barriers that hinder the access and participation of PWDs.

Figure 3.1: Matrix of Community-based Rehabilitation



Source: WHO (2010).



In the context of PWDs' access to health services access, Article 12 of Law No. 8/2016 on Persons with Disabilities ensures the right of PWDs to receive health services. Presidential Decree No. 82/2018 on Health Insurance guarantees that each participant has the right to receive health insurance benefits, which include promotional, preventive, curative, and rehabilitative services.

The Ministry of Health has launched the 2020–2024 Disability Inclusion Health Service Roadmap as a reference for policies and programmes for all central and regional levels of health services. This roadmap includes seven main strategies that refer to the WHO Disability Action and Health System Strengthening.

Related to developmental disabilities, the Ministry of Health has developed a programme for the stimulation, detection, and early intervention in growth and development for children under 5 years, aimed at detecting early growth and development disorders. Currently, there are 7,331 public health centres (Pusat Kesehatan Masyarakat – Puskesmas) have implemented the programme for early detection and early intervention. Additionally, 27 hospitals have received training to serve as referral hospitals for growth and developmental disorders.

#### *Support for education, work, and livelihoods of persons with developmental disorders*

The Government of Indonesia ensures that education units are accessible and inclusive for PWDs through the implementation of Inclusive Education, as mandated in Minister of Education and Culture Regulation No. 16/2007. To enhance the quality of inclusive education, the government collaborates with companies to provide employment opportunities for PWDs and works with contractors to improve access to school infrastructure.

In the education process, special assistance and printed literature are provided during tests and examinations to students with disabilities and special needs. Financial and human resource assistance allocated to inclusive education includes grants for regular schools implementing inclusive education, special advisory teachers, seminars, and workshops related to inclusive education.

Regarding early intervention for children with autism, in 2013, the Ministry of Education and Culture initiated the establishment of autism centres in 29 different cities and provinces. These centres provide early interventions for children with autism and support systems for parents.

Under the coordination of the Ministry of Social Affairs, several programs are being conducted for PWDs:

- Disability Enterprises: a form of continuous development for vocational rehabilitation, providing job training, special needs facilities, and employment opportunities for PWDs.

- Program Keluarga Harapan (PKH) or Hope Families: a conditional social assistance programme targeted at poor families who are eligible to be PKH recipients.
- Cards for Persons with Disabilities: In 2020, there were 17,000 disabilities cardholders in Indonesia. The DKI Jakarta provincial government also distributes similar cards with specific benefits, such as cash assistance of Rp 300,000/month, free services using the city bus transportation system (Transjakarta) in 13 corridors, and subsidised food.

To provide work opportunities for PWDs, the Ministry of Manpower has conducted several programmes, as follows:

- In implementing the minimum quota of employment for PWDs, the Ministry of Manpower signed a memorandum of understanding with state-owned enterprises regarding the placement and training of workers with disabilities.
- Community Training Centre (abbreviated as BLK): assistance programme for workers and labor unions. The government has built 1,113 community BLKs aimed at increasing the competence of workers and improving their welfare.

The Ministry of Education and Culture has taken measures to ensure the participation of PWDs in cultural life, recreational, and sports activities by developing infrastructure standards for schools accessible for children with disabilities. During the National Paralympic Week 2020, the Ministry of Social Affairs carried out several activities: (i) public education on inclusivity and alignments for PWDs; (ii) monitoring and evaluation for accessibility in facilities and venues, and (iii) training of trainers for paralympic athletes' assistants.

PT Angkasa Pura, a state-owned enterprise managing airports in Indonesia, developed the concept of autism-friendly airport by providing training to airport staff on how to assist families of children with autism. A multisensory room is provided as a calming space for the children.

#### *Advocacy and empowerment*

To prevent discrimination against PWDs in jobs, especially women, the Ministry of Women Empowerment and Child Protection has been conducting advocacy on cases of discrimination in employment and skills training for women with disabilities since 2016.

Article 5 of Law No. 7/2017 on General Elections states that 'Persons with disabilities who meet the requirements have the same opportunity as voters and as candidates for members of the House of Representative and Regional Representative Board, President/Vice President, members of the Regional House of Representative, and as election organisers'.

The General Election Commission issues various regulations to ensure accessibility during general elections. These regulations include ensuring accessibility at voting places, providing assistance by election officers and appointed assistants, and offering aid devices for visually impaired voters at various levels.

The Ministry of Social Affairs has implemented various service programmes to fulfill the rights of PWDs. These programmes include business assistance, assistive devices, vocational training, cash social assistance, and social rehabilitation (both family and community based).

#### *Issues to address: The different needs of persons with developmental disorder*

Since 2016, the Government of Indonesia enacted a Law on Person with Disabilities and its subsidiary regulations to supervise the implementation of policies and practices related to disability issues. However, it is important to acknowledge the specific needs of individuals with developmental disabilities, such as ASD, ADHD, and learning disorder, which differ from the needs of those with physical and sensory disabilities.

Based on the interview with key informants, it is recommended to conduct proper and continuous needs assessments to develop appropriate policies and practices for individuals with developmental disorders. The government, families, PWDs, and other stakeholders must collaborate to help those with developmental disabilities unlock their potential, adapt to everyday challenges, and enjoy a good quality of life.

In the future, several areas need to be improved, including:

- Early assessment and diagnosis (standardised assessment tools, training for health workers and professionals, identification of prevalence);
- Best practices in early interventions (certifications for therapists, parents' involvement, improvement in the availability of services);
- Improving the quality of inclusive education (special needs teachers, counseling services, a safe physical and social environment);
- Working opportunities (job coaches, a minimum quota of employment); and
- Services for adults with development disabilities (providing support groups for parents and siblings, and residential and group homes).

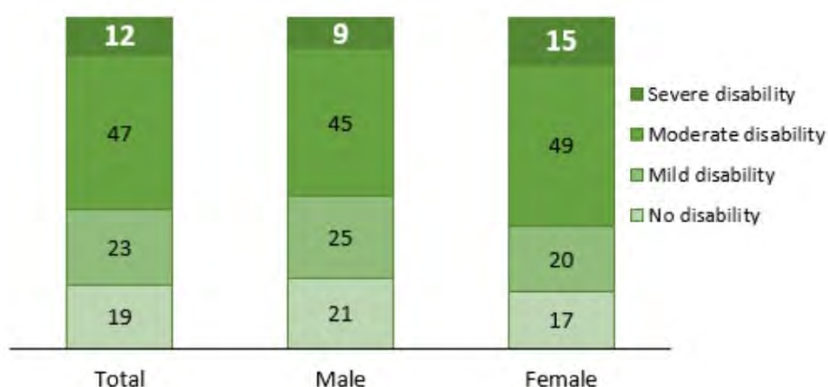
### **3.2 Philippines**

#### *Data of PWDs*

Based on 2010 statistics, 1.57% of the Philippine population is PWDs (CPH, 2010). According to a more recent database from the Philippine Statistics Authority, which conducted the National Disability Prevalence Survey or Model Functioning Survey in

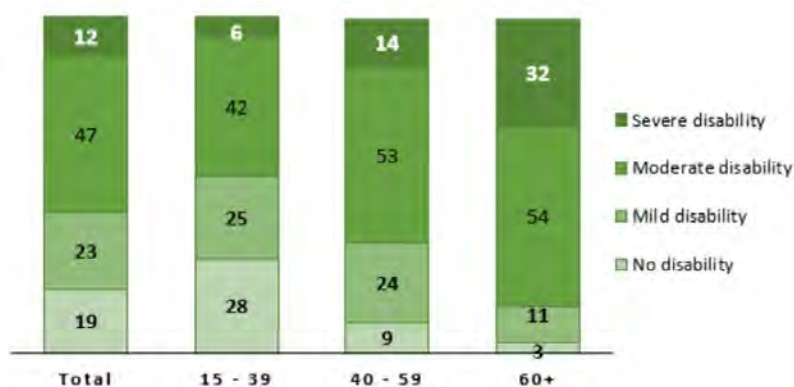
2016, 12% of Filipinos ages 15 and older experienced severe disabilities. The survey is based on the International Classification of Functioning, Disability and Health, which views disability as a continuum, a matter of degree ranging from no disability (0 score) to extreme disability (100 score). However, the data were not disaggregated according to types of disabilities, despite the varying levels of disability, as indicated in Figures 3.2 and 3.3 (Lisa, 2019).

Figure 3.2: Percentage Distribution of Population Age 15 and Older by Disability Level and Sex: Philippines, 2016



Source: Philippine Statistics Authority (2016).

Figure 3.3: Percentage Distribution of Population Age 15 and Older by Disability Level and Age Group: Philippines, 2016



Source: Philippine Statistics Authority (2016).

Other specific data regarding disability are issued by DOH, based on the Philippines Registry for Persons with Disability, a national registration and reporting system designed to capture data on issued identities for PWDs. As of May 2022, registered PWDs total 605,349; by the end of 2022, registered PWDs will reach 1 million.

- The Philippine DOH Administrative General listed 10 disability types, including eight disability types and two newest categories under two special laws – Republic Acts (RAs) 11215 and 10747 – which considers persons with cancer and rare diseases as PWDs. As such, the government estimates that 1.5 million PWDs in the Philippines under 10 types of disabilities: physical disability, deaf/hard of Hearing, intellectual disability, learning disability, mental disability, psychosocial disability, speech impairment, visual disability, cancer, and rare disease.

Another source listed the types of disabilities as conditions that may affect 17 functioning domains: (i) mobility, (ii) hand and arm use, (iii) self-care, (iv) seeing, (v) hearing, (vi) pain, (vii) energy and drive, (viii) breathing, (ix) affect (depression and anxiety), (x) interpersonal relationship, (xi) handling stress, (xii) communication, (xiii) cognition, (xiv) household tasks, (xv) community and citizenship participation, (xvi) caring for others, and (xvii) work and schooling.<sup>3</sup>

#### *Definition and prevalence of developmental disorders*

In the Philippines, 'developmental disability' refers to activity limitation and/or participation restriction secondary to a delay, regression, or loss in the developmental milestones of a child. It can be neurological or non-neurological in origin. Specifically, PhilHealth Circular No. 2017-0029 states that 'Developmental disability refers to the manifestation of delays, regressions, or deviations in the cognitive-adaptive, sensorimotor, communication, social, emotional, or behavioral developmental domains of a child. This condition begins during the developmental period of the child; therefore, timing is important in potentially mitigating the impact of such a disability'.

As such, developmental disability may affect the following domains: (i) cognitive and adaptive; (ii) speech and language (communication); (iii) social and emotional (behavioural); and (iv) motor (gross and fine).

RA 11650, the regulation related to developmental disabilities, identifies two types of disabilities under developmental disabilities: learning and intellectual. Learning disabilities represent some impairment in several areas, including listening, thinking, and other academic areas. Individuals with intellectual disabilities have difficulty in learning, specifically in applying what they have learned and acquiring new skills.<sup>4</sup> The

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<sup>3</sup> Data collected from interview sessions with experts on developmental disabilities from Philippines, Ranilo S. Sorongon (Council for the Welfare of Children) and Marie Therese A.P. Bustos (special education scholar) in April–June 2022.

<sup>4</sup> Data collected from interview sessions with Emerito L. Rojas, former Executive Director of Philippines National Council on Disability Affairs (NCDA) in April–June 2022.

current data of registered persons with learning disabilities and intellectual disabilities is 71,274 people with 24,657 people with learning disabilities and 46,617 (per April and May 2022), constituting 13.59% of the total PWD population. Another unpublished source provided larger data: around 1.6 million cases of developmental disabilities are estimated amongst children under the age of 19 (Philippine Health Insurance Corporation, 2018 ).

A more specific category under developmental disabilities is listed by the Department of Education in the categories (Table 3.2).

**Table 3.2: Categories Related to Developmental Disabilities**

Diagnosed	Undiagnosed but with Manifestations
<ul style="list-style-type: none"> <li>• Learning disability</li> <li>• Intellectual disability</li> <li>• Autism spectrum disorder</li> <li>• Multiple disabilities</li> <li>• Cerebral palsy</li> <li>• Speech/language disorder</li> <li>• Emotional/behavioural disorder</li> <li>• Orthopedic/physical handicap</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulty in remembering, concentrating, paying attention, and understanding</li> <li>• Difficulty in applying knowledge</li> <li>• Difficulty in applying adaptive skills</li> <li>• Difficulty in displaying interpersonal behaviour</li> <li>• Difficulty in mobility (walking, climbing, and grasping)</li> <li>• Difficulty in communicating</li> </ul>

Source: Interview data (2022).

Based on Table 3.2, developmental disabilities include the diagnosis of eight categories as listed. Another source lists four leading developmental disabilities in the Philippines: ASD, ADHD), Cerebral Palsy, and Global Developmental Delay (Philippine Health Insurance Corporation, 2018).

#### *Legal system and disability-related policies*

The Department of Social Welfare and Development plays a key role as the central agency for disability administration. Other government agencies are involved in addressing education, health, and employment issues for PWDs, including the Department of Education, DOH, and Department of Labor and Employment. Table 3.3 lists Philippine laws and policies related to PWDs, including those with developmental disabilities.

**Table 3.3: Philippine National Laws and Policies Related to Developmental Disorders**

Philippines Laws and Policy	Disability Specific Laws
<ul style="list-style-type: none"> <li>• RA 11036 – The Mental Health Act</li> <li>• RA 11223 – Universal Health Care Act</li> <li>• RA 10121 – Philippine Disaster Risk Reduction and Management Act</li> <li>• RA 10821 – Children’s Emergency Relief and Protection Act</li> <li>• RA 10354 – The Responsible Parenthood and Reproductive Health Act of 2012</li> </ul>	<ul style="list-style-type: none"> <li>• RA 7277 – Magna Charta of Persons with Disabilities</li> <li>• RA 9442 – Privileges and Benefits of Persons with Disabilities</li> <li>• Section on the prohibition of vilification and ridicule against persons with disabilities (PWDs)</li> <li>• RA 11228 – An Act Providing for the Mandatory Philhealth Coverage for All Persons with Disability</li> <li>• RA 10524 – An Act Expanding the Positions Reserved for PWDs</li> <li>• PhilHealth Circular No. 2017-0029 – Z Benefits for Children with Developmental Disabilities</li> </ul>

Source: Interview data (2022).

*Access to healthcare and disability support and services for developmental disorders*

The government has issued several programs, procedures, and facilities for early detection and intervention programmes or therapies. Policies related to early screening and detection are regulated under RA 9288 or the Newborn Screening Act of 2004.

Acting as the primary agency from the government is the Early Childhood Care and Development (ECCD) Council. This government agency supports programmes that cover health, nutrition, early education, and social services for children aged 0–4 years, including those with developmental delays and disabilities in early learning programmes. The ECCD issues checklists to determine if a child is developing adequately or is at risk for developmental delays. The checklist can be used by service providers such as teachers, rural health midwives, child development and daycare workers, parents and caregivers who can easily administer it after a brief training period.

The Philippine Health Insurance, or PhilHealth, is a government social insurance programme that provides health services, including those for PWDs, at a low monthly cost. In 2018, PhilHealth launched a ‘Z Benefit Package’ to offer a set of services for children with developmental disabilities. The services provided include assessment and planning by medical specialists and allied health professionals (e.g. occupational, physical, and speech therapists), using applicable standardised tests, including rehabilitation therapy.

During the COVID-19 period, the National Council of Disability Affairs (NCDA) partnered with rehabilitation specialists to launch the Teletherapy Project for children with

disabilities, including those with developmental disabilities. The Teletherapy Project offers online therapy services since therapy and rehabilitation centres were closed during the lockdown. The provision of supporting technology tools, such as tablets, was also facilitated to broaden access to online therapies, rehabilitation, and education. Civil society organisations, such as Autism Society Philippines (ASP), also provide family support, including workshops, to help parents overcome mental challenges related to raising autistic children.

#### *Support for education, work, and livelihoods of persons with developmental disorders*

In terms of education, the Department of Education has established 468 special education (SPED) centres. These centres have at least one designated SPED teacher to cater to the needs of students. Currently, 17 SPED centres have been converted into Inclusive Learning Resource Centre (ILRC) as mandated by RA 11650. This law stipulates that all public schools nationwide are required to identify learners with special needs and provide them with free basic and quality education. It also mandates that all cities and municipalities have at least one ILRC.

Under the Department of Social Welfare and Development, several centres for rehabilitation and vocational training have been established in various areas, such as the National Vocational Rehabilitation Centre (Quezon City), Area Vocational Rehabilitation Centre (Cebu, Zamboanga, Pangasinan), and the Rehabilitation Sheltered Workshop (Quezon City).

The involvement of disability organisations, NGOs and civil society is considered an important role to support the government for developing access for developmental disorders. Some of the organizations, including ASP, ADHD Society, Down Syndrome Association of the Philippines, Leonard Cheshire Disability, The Philippines Foundation, Inc., and NORFIL Foundation, develop and conduct numerous programmes and trainings, including parent trainings and workshops for persons with developmental disorder. For example, the ASP conducts regular family support groups meetings, sibling support and workshops, and parents' training to apply and continue the interventions for their child at home. They also conduct employability training for autistic persons and sensitivity training to guide employers for a sustainable process of assimilating autistics persons into the workforce.

#### *Advocacy and disaster mitigation*

There is a need to strengthen public advocacy on disabilities, in general, and developmental disabilities, in particular, to counteract misconceptions about disabilities.

As one of the countries at high risk of disasters, the Philippines has enacted legislation to prepare for disaster mitigation (RA 10121). The country also established the Centre for Disaster Preparedness, which specialises in implementing humanity and inclusion



principles, conducting training and advocacy, and promoting disability inclusion in the Disaster Risk Management Framework.

The NCDCA has partnered with the Office of Civil Defense in the Department of Civil Defense to develop a manual on disability-inclusive disaster rescue and response and mitigation. One of the goals is to educate front-liners and rescuers on how to identify children with disabilities, including those with developmental disabilities, to implement rescue plans during disasters. It will also involve comprehensive training for front-liners and PWDs, ensuring that essential life-saving and life-sustaining services are provided to communities affected by disaster events.

#### *Issues to address: Access to services and lack of comprehensive data*

Based on the interview data, several issues need to be addressed for PWDs, including:

- The absence of an overall service framework, which should serve as a guide to provide integrated and cohesive policies, programmes, and services.
- The lack of updated and comprehensive data, which may serve as the basis for the plans and programmes identified by national government agencies.
- The prevalence of poverty at the local level also contributes to the overall dire situation.
- Funding allocation and the overall socioeconomic situation of the local government unit may limit the implementation of programmes and services for PWDs
- Access to local programs and services also depends highly on the priorities and plans of the local chief executive.

One critical issue to be addressed is the need to strengthen the country's data collection on PWDs. Until recently, concerned agencies have made efforts to collect data for their respective programmes and services. However, there is no working system yet to maintain an updated and comprehensive database for PWDs, including disaggregated information.

### **3.3 Viet Nam**

#### *Data of persons with disabilities*

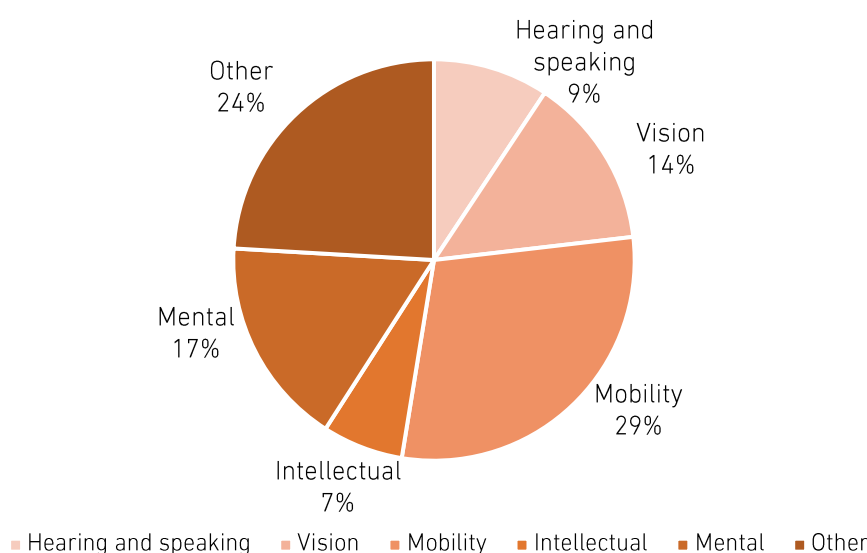
The National Survey on Persons with Disabilities (VDS) in 2016 reported a disability prevalence of 7.06% amongst the population aged 18 and older, and a disability prevalence of 2.83% amongst children aged 2–17. The most common type of disability amongst children is psychosocial disability, followed by communication and cognitive disabilities. In total, 6.2 million people, representing 6.7% of the total population (90

million people) have disabilities (General Statistics Office, 2016).

Disability is categorised into six: (i) vision, (ii) hearing and speaking, (iii) mobility, (iv) mental, (v) intellectual, and (vi) others. It also differentiates between severity levels (Figure 3.4).

There is a shortage of data on specific groups of PWDs in Viet Nam, particularly persons with developmental disorders, including autism, ADHD, and learning difficulties. The General Statistics Office has proposed 53 indicators to be disaggregated by disabilities, covering 10 Sustainable Development Goals (VNA, 2022). The indicators are expected to provide more evidence for the development of disability-inclusive socioeconomic policies and programmes (VNA, 2022).

Figure 3.4: Distribution of Disability Types in Viet Nam



Source: Compiled by Vietnam Autism Network (VAN, 2022) from the National Survey on PWD, 2016

### *Definition and prevalence of developmental disorders*

Specific data and statistics on intellectual disabilities and developmental disorders amongst children in Viet Nam are still unknown due to a lack of systematic epidemiology studies and differences in terms of definitions.

Developmental disorders refer to a group of conditions with onset in the developmental period. The disorders typically manifest early in development, often before the child enters grade school, and are characterised by developmental deficits that produce impairments in personal, social, academic, or occupational functioning. The range of developmental deficits varies from very specific limitations in learning or control of executive functions to global impairments in social skills or intelligence. Neurodevelopmental disorders frequently co-occur (as in DSM-5), but there is usually

one major disorder that exists.<sup>5</sup>

Due to the limitation of existing epidemiological data for several specific disabilities in Viet Nam, persons with developmental disorders have different prevalence rates. For example, a recent study reported a prevalence for autism ranged between 0.42% and 0.75% (Hoang et al., 2019), while another study suggested a range between 0.5 and 1%. Since the late 1990s, autism (*tự kỷ* in Vietnamese) has been recognised as a condition. Despite the absence of official data on autism prevalence in Viet Nam, it is estimated that in 2012, 160,000 people had ASD in the country (Ha, et al., 2014). In contrast, the 2020 data provided by the Asia-Pacific Development Center on Disability of Thailand, with support from Japan-ASEAN Integration Fund (JAIF) and the ASEAN Autism Network, suggested that about 200,000 people with autism were recorded in Viet Nam (Panyasirimongkol et al., 2020a).

Different data issued by the National Pediatrics Hospital between 2016 and 2018 on developmental disorders in Viet Nam listed the prevalence numbers of developmental disorders as follows: (i) pervasive developmental disorder: 18.26%, (ii) attention deficit-hyperactive disorders: 18.01%, (iii) speech and language specific disorders: 17.87%, and (iv) delayed mental development: 10.80%.

The 2016 National Survey on People with Disabilities (VDS) collected administrative data from disability-care centres or institutions. Interestingly, people with psychosocial and intellectual disabilities were reported to be the largest groups of people currently receiving institutional care (5.3% and 31%, respectively). Children and young people (aged below 30) accounted for nearly 40% of PWDs living in these institutions.

#### *Access to healthcare and disability support and services for developmental disorders*

Children and youth with intellectual and developmental disorders are amongst the most disadvantaged and vulnerable groups.

Limited research evidence from Viet Nam suggests significant gaps in the provision of general healthcare, rehabilitation, education, and social services and support for children with intellectual and developmental disorders, as well as for their families. The following points illustrate the situation amongst families of children with intellectual and developmental disorders in Viet Nam based on the interview conducted with Vu Song Ha from CCIHP in 2022<sup>6</sup>:

- The situation is exacerbated for children and families living in rural and remote areas with lower socioeconomic backgrounds. This is due to limited access to

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<sup>5</sup> Data collected from interview sessions with Nguyễn Thị Kim Hoa, special education expert from National Centre for Special Education, Viet Nam, in November 2022.

<sup>6</sup> Data collected from interview sessions with Vu Song Ha, expert on autism and mental health studies from Center for Creative Initiatives in Health and Population (CCIHP), Viet Nam, in October 2022.

services, underdeveloped infrastructure, low public awareness about disability, and restricted financial and human resources.

- There are services for diagnosis and rehabilitation, but they are only available in a few hospitals at the central level or at project sites. Though there are some efforts to strengthen the capacity of service providers working with children with developmental disabilities, including training programmes on occupational therapy, speech therapy, developing and coaching for multidisciplinary rehabilitation teams for 12, 9, and 2 years, health service providers still need further training and clinical coaching. For example, the provision of regular developmental checkups, monitoring at health facilities, and multidisciplinary intervention services are needed.
- There are 63 hospitals and rehabilitation centres nationwide, with 100% of central general hospitals having rehabilitation departments. Additionally, 90% of general hospitals and 40% of provincial specialised hospitals have rehabilitation departments, while 70% of district hospitals have rehabilitation departments or combined with other departments (Eitel and Vu, 2017).
- Community-based rehabilitation (CBR) was introduced in Viet Nam in 1987 and was an important component of the Targeted Program on Health for 2012–2015. The programme has been implemented in 51 provinces and cities in Viet Nam.
- CBR programmes for PWDs are implemented in coordination with the health, education, and labor invalids and social affairs sectors, with the Ministry of Health (MOH) and Ministry of Labour, Invalids, and Social Affairs (MOLISA) playing major roles in these programme (MOH and MOLISA, 2020).

In addition, based on the interview with VAN in 2022, the country provides several healthcare services and facilities for PWDs. Children under 6 years old have health insurance; those with disabilities receive health insurance and welfare (if applicable). For PWDs in the severe and special severe categories, 1.1 million PWDs have obtained health insurance cards out of a total of 6.2 million PWDs. In Viet Nam, 12 universities with medical programmes offer rehabilitation training. There are 6,327 medical staff with rehabilitation certificates, including 6,000 physical therapists, 107 occupational therapists, 20 speech therapists, and 200 orthopedic specialists (Interview with VAN, 2022).

#### *Support for education, work, and livelihoods of persons with developmental disorders*

Viet Nam introduced its inclusive education policy since the government passed the Law on Universal Primary Education in 1991 the Law on Education, and reinforced by Decree 23/2006/QĐ-BGD&ĐT on inclusive education for PWDs (MOET, 2006; Ha et al., 2014).

Public schools and kindergartens are expected to accept children with disabilities on a regular basis, but parents experience difficulties in enrolling their children in both public and private schools (Ha et al., 2014).

This is due to the lack of school accessibility for children with disabilities, especially for those in higher levels of education: 33.6% of children with disabilities attend school at the appropriate age in secondary schools; 2.9% of schools have appropriate design; 8.1% of schools have pathways for PWDs; and 9.9% of schools have sanitary facilities suitable for children with disabilities.

Based on the interviews with VAN (2022), nearly 20 centres have been supporting the development of inclusive education in 20 provinces and 107 public special education institutions in Viet Nam. However, compared to the number of children with disabilities, the number of facilities is too small. The number of children with disabilities attending inclusive schools from 2011 to 2021 increased 10 times compared to the previous period from 2000 to 2010 (interview with VAN, 2022).

In Viet Nam, social services programmes for persons with developmental disabilities, particularly those with autism, are implemented by emphasising the support system in the context of accessibility. For example, there are three accessibility programmes for persons with autism: (i) traffic and transport accessibility, (ii) construction of a disability-friendly buildings, and (iii) enhanced communication using ICT for PWDs, including those with autism. Additionally, programs related with recreational activities such as art and culture, sports and tourism were also conducted for individuals with autism (Panyasirimongkol et al., 2020a).

On 26 April 2013, the Prime Minister issued Decision No. 647/2013/QĐ-TTg to approve the project for taking care of helpless orphans, abandoned children, HIV/AIDS-infected children, child victims of chemical toxics, children with severe disabilities, and children affected by natural disasters and accidents, relying on the community (2013–2020). The content of the project includes building models of caring and assistance facilities for children with autism, Down Syndrome, intellectual disabilities and other groups of disabled children.

In 2019, there was D17,517 billion (Vietnamese dong), or around US\$700,000 of state budget allocated for social protection beneficiaries, including monthly allowances and funds for purchasing health insurance cards (referencing Decree No. 136/ 2013/ND-CP dated 21 October 2013 of the government).

In July 2021, according to Decree 20/2021/ND-CP, PWDs are entitled to receive social welfare funds as follows:

- Person (16 to under 60 years old) with severe disabilities receive D540,000 (around US\$22) per month
- Person (under 16 or over 60 years old) with severe disabilities receive D720,000 (around US\$30) per month

- Person (from 16 to under 60 years old) with special severe disabilities receive D720,000 (around US\$30) per month
- Person (under 16 or over 60 years old) with special severe disabilities receive D900,000 (around US\$37) per month
- Depending on localities, individuals with disabilities can also receive additional welfare.

### *Legal system and disability-related policies*

The regulatory framework for laws and policies related with developmental disabilities in Viet Nam follows the United Nations Convention on the Rights of Persons with Disabilities (ratified by Viet Nam in 2014) and implemented in the National Action Plan to enact the 2030 Agenda for Sustainable Development Goals.

In August 2020, the government issued Decision No. 1190/QĐ-TTg of the Prime Minister, which was to approve the programme on supporting PWDs in 2021–2030 period. The implementation of Party and State policies to meet the basic needs of PWDs in terms of healthcare and social services still face many difficulties due to the lack of resources, limited access to rehabilitation services and social services for PWDs, and limited state budget compared to the actual needs. Table 3.4 lists Viet Nam's current laws and policies related to developmental disorders.

**Table 3.4: Viet Nam National Laws and Policies Related to Developmental Disorders**

Viet Nam Laws and Policies	Disability Specific Laws
<ul style="list-style-type: none"> <li>– Decree No. 136/ 2013/ND-CP on Social Protection Policy dated 21 October 2013 of the government.</li> <li>– The United Nations Convention on the Rights of Persons with Disabilities (ratified by Viet Nam in 2014).</li> <li>– The National Action Plan to implement the 2030 Agenda for Sustainable Development Goals.</li> </ul>	<ul style="list-style-type: none"> <li>– The Directive No. 39-CT/TW dated 1 November 2019 of the Central Secretariat of the Communist Party of Viet Nam on strengthening the Party's leadership in the work of PWDs.</li> <li>– Directive No. 43-CT/TW dated 14 May 2015 of the Central Secretariat of the Communist Party of Viet Nam on Strengthening the Party's leadership over the settlement of the consequences of Agent Orange used by the US in Viet Nam.</li> <li>– The Law on Persons with Disabilities No. 51/2010/QH12 and documents detailing and guiding the implementation of a number of articles of the Law on Persons with Disabilities (The consolidated document No. 763/VBHN-BLDTBXH dated 28 February 2019 of Ministry of Labour, Invalids and Social Affairs).</li> <li>– Decision No. 753/QĐ-TTg dated 3 June 2020 of the Prime Minister promulgating the implementation plan of Directive No. 39-CT/TW</li> </ul>

	<p>dated 1 November 2019 of the Central Secretariat of the Communist Party of Viet Nam on strengthening the Party's leadership in the work of PWDs.</p> <p>– Decision 1190/QĐ-TTg dated 5 August 2020 of the Prime Minister approving the programme supporting PWDs for the period 2021–2030.</p> <p>– Decision No. 1929/QĐ-TTg dated 25 November 2020 of the Prime Minister, approving the social assistance and rehabilitation programme based on the community for autistic children, persons with psychosocial and mental disorders in the period 2021–2030.</p>
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Source: Interview data (2022).

### *Issues to address: Discrimination and employability*

Based on the interviews and previous research related to developmental disabilities (and other disabilities) in Viet Nam, there are several issues that need to be addressed:

- Discrimination against PWDs is a barrier to their participation in society.
- Stigma and low employability index: According to a survey, 55% of respondents believed that employers were unwilling to hire PWDs, and 42.7% of respondents thought that children with disabilities should not go to school.
- Many PWDs, including those with mobility impairment, intellectual disabilities, and developmental disorders, face challenges in fully accessing health, orthopedic, rehabilitation, and occupational therapy services.
- Support services for children with autism in local and rural areas lack quality, including early detection, intervention, consultation, psychological therapy, rehabilitation, and special education.
- Technical protocols, healthcare assurance for various techniques, and mental health support are needed for persons with developmental disorders and their families.
- Based on the interviews with the key informants, the following steps can improve the well-being of individuals with developmental disorders in Viet Nam: (i) enhance the roles and effectiveness of the National Committee on Persons with Disabilities in promoting activities to care for disabled and elderly individuals; (ii) develop more efficient implementation of the Law on Persons with Disabilities and increase social assistance funding from 1.5% to 3% of the gross domestic product; and (iii) raise awareness of social assistance and care for individuals with disabilities, and promote more inclusion and participation of persons with developmental disabilities in the community.

## Chapter 4

# Perspectives of Persons with Developmental Disorders and their Families in Southeast Asia

### 4.1 Persons with developmental disorders and families

For persons with developmental disorders, parents and families play an important role in facilitating their access to healthcare and education from childhood to adult life. During childhood, parents and caregivers should be adequately supported to access early childhood developmental interventions (Collins, et.al., 2017). As individuals with developmental disorders enter their teen and adult years, they should receive ongoing support, taking into account the varying conditions that they may have. Ideally, their families and the supporting environments, including caregivers and communities, can be prepared to accommodate the needs of persons with developmental disorders, achieving maximum social inclusion and functioning (Collins et al., 2017).

Previous studies on caregivers of autistic children in Malaysia have highlighted some issues in caregiving, such as a lack of quality time with other family members, additional concerns about their children's education and future employment, and financial difficulties in accessing quality services for their child (Jamir Singh et al., 2023; Sitimin et al., 2017). These challenges can potentially impact the psychological well-being and quality of life of families and caregivers, leading to negative attitudes and stress (Jamir Singh et al., 2023; Isa et al., 2016).

From our interviews and surveys, we gathered some important issues from the perspectives of persons with developmental disabilities and their families in Indonesia, the Philippines, and Viet Nam. These areas were identified as critical for the rights of PWDs. These issues are (i) employment and job training, (ii) advocacy and activism, (iii) community life, (iv) group home and funding support, (iv) judicial procedure and decision-making support, (v) disaster mitigation and crisis support, and (vi) research on developmental disorders. These will be explained in the next sections.

### 4.2 Employment and job training

Having a job provides individuals with a sense of purpose and self-worth. For many people, it is a form of self-actualisation that can also improve their financial condition and social connections (NACBHDD, 2018). Every person, regardless of disability, deserves the opportunity to be full members of their community, where they can live, learn, and work throughout all stages of life (NACBHDD, 2018). Nevertheless, after completing their education and training programmes, persons with developmental disabilities face various challenges and obstacles in securing jobs.

There is a significant gap in the employment rate for working-age adults with disabilities,



and those with developmental disabilities might have fewer opportunities for formal sector jobs (see Chapter 2 in this report). According to data from Indonesia, for example, the number of employees with mental and intellectual disabilities is lower than the overall population of disabled employees (see Chapter 2). This concerning situation makes most of the parents worried, especially individuals with developmental disabilities themselves, as their abilities may not align with the demands of the workplace. Consequently, many of them remain at home, unemployed, and unable to contribute financially.<sup>7</sup>

Based on 2023 interview data, there are several factors why adults with developmental disorders encounter difficulties in getting a job:

- Lack of awareness from stakeholders, either the policy makers or companies (employers/recruiters). In this case, both policy-makers and companies (employers) need to be equipped with knowledge and understanding to improve access to work opportunities for persons with developmental disorders.
- Despite regulations providing quotas for PWDs in some AMS, the competition for jobs is very high. (Indonesia, for example, has a regulation requiring a 2% employment quota for PWDs in government and 1% in the private sector.) The lack of implementation of government regulations regarding the disability service unit in the employment sector for PWDs remains a problem.
- Low societal expectations towards individuals with developmental disorders can lead to discrimination in job opportunities. The lack of supporting services, such as transportation, accommodations, and assistive technology, can also pose potential challenges hindering persons with developmental disorders from getting employed.
- Other challenges for individuals with developmental disorders include a lack of work experience upon graduation. Work training or job coaching can be a solution to provide support for persons with developmental disorders in navigating the workplace. Through job coaching and training, they can learn the entire recruitment process, starting from interviews, adapting to the workplace, as well as learning work strategies, including communication with employers and other staff.

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<sup>7</sup> Data collected from interview sessions with Yayasan Autisma Indonesia representatives, Adriana Ginanjar and Taufiq Hidayat, March–August 2023.

#### Box 4: Philippines' Project Inclusion Network

One example of a job training programme for persons with developmental disabilities is offered by Project Inclusion Network (PIN) in the Philippines. The nonprofit organisation's primary goal is to promote workplace inclusion. PIN follows an access-to-work model that prepares jobseekers and employers, supporting their transition into an inclusive community (<https://projectinclusion.ph/>). They have successfully trained persons with developmental disabilities and partnered with the Philippine drugstore company Southstar Drug to create opportunities for persons with disabilities (PWDs).

Since 2018, Southstar Drug collaborated with PIN to place individuals with disabilities, including those with developmental disabilities, in several of their branches. Many of them are now regular employees. In 2020, the company employed 23 individuals with disabilities (Southstar Drug, 2020).

For employers, PIN has developed a model called 'Employer Engagement Process', which begins with workplace preparation to create an initial workplace inclusion plan for the organisation. The second step involves conducting a worksite walkthrough to assess the intervention needs of the employer for building an inclusive employment process for PWDs, including the job matching process for potential employees. The nonprofit organisation also facilitates Disability Sensitivity Training and Transition Support Visit to assess the necessary interventions for an effective workplace transition for both the employee and the employer (<https://projectinclusion.ph/>).

### 4.3 Advocacy and activism

To ensure full inclusion and participation of persons with developmental disorders in the community, continuous advocacy and activism are needed. Historically, parent-led support groups and advocacy have become an increasingly common aspect of public discourse for children and persons with developmental disabilities, mainly in the context of their health and educational needs (Bertilsdotter Rosqvist, Brownlow, and O'Dell, 2015). Recently, the emergence of the neurodiversity movement has driven self-awareness amongst autistic adults and other developmental disabilities groups, including ADHD groups, which leads to self-advocacy movements mainly through online platforms and offline activism. Both parent-led advocacy and self-advocacy movements are considered equally important for several reasons:

- Empowering individuals with developmental disabilities. Conducting self-advocacy for persons with developmental disabilities means they can speak on behalf of themselves and make their own choices. Self-advocacy helps them to get more access to resources and services they need to live independently and participate fully in their communities.
- Raising public awareness. Advocacy raises public awareness about the challenges faced by persons with developmental disorders. Creating public awareness can help break down stereotypes and misconceptions, as well as

educate the public about the importance of inclusion and the value of diversity (AAIDD, 2020).

- Policy changes. Advocacy can lead to policy changes that improve the lives of persons with developmental disorders. For example, advocacy efforts supported by parent-based autism organisations in the Philippines aimed to propose a bill emphasising the needs and welfare of autistic individuals (Box 5a).
- Community building. Advocacy can help build stronger, more inclusive communities that support individuals with developmental disorders. It can also create networks of support for families and caregivers.

In conclusion, advocacy for developmental disabilities is crucial because it ensures that persons with developmental disabilities are treated with dignity and respect, have access to the resources and services they need, and can live full and meaningful lives. In the following part (Box 5b), two examples from the Philippines are presented: one detailing how organisations play a role as advocates for policy changes in establishing centres for autism, and another illustrating how the self-advocacy movement conducts an awareness campaign for inclusivity in higher education institutions.

#### Box 5a

##### Case 1: The Autism Society of the Philippines (ASP) and the Bill on Autism

As the pioneering organisation on autism in the Philippines, the ASP has been supporting advocacy efforts, mainly to propose bills for enhancing the support and benefits for individuals with autism and their families. In 2023, several bills were proposed in the legislature – mainly about the establishment of health services and facilities – under the Health Committee, which also involves members of Congress with autistic children.

In April 2023, two separate bills were proposed to establish the Centre for Autism in the Philippines. The centre is proposed to be funded by the government to help alleviate the burden for indigent patients and their families (Torregoza, 2023). In the proposed bills, ASP is also involved in the National Autism Board, which is suggested to be under the Office of the President, to govern the proposed Centre for Autism in the Philippines. The centre will establish diagnostic, therapeutic, and rehabilitation clinics; provide vocational training programmes for autistic adults; and extend free diagnostic and rehabilitation services for indigent individuals with autism (Abasola, 2023). It will also propose training programmes for teachers, therapists, and other medical professionals who will aid children and adults with autism. In January 2024, The Neurodivergent People's Rights Act (Philippines) is filed as House Bill No. 9787, with objectives to promote inclusivity and support for neurodivergent individuals (including Autism, ADHD, Down Syndrome, Cerebral Palsy, Global Developmental Delay, Intellectual and Learning Disabilities, Motor and Communication Disorders, and other Neurodevelopmental Disorders). The bill aims to eliminate stigmas and discrimination associated with neurodevelopmental differences.

Source: Compiled by authors (2023).

### Box 5b

#### Case 2: The ADHD Society of the Philippines and Philippine Dyslexia Foundation

ADHD (Attention deficit hyperactivity disorder) is a developmental disorder associated with an ongoing pattern of inattention, hyperactivity, and/or impulsivity (NIMH, 2021). Persons with ADHD may experience the aforementioned symptoms, which can interfere in their daily activities and relationships. ADHD can change over time as the person ages, but it typically begins in childhood and can continue into the teen years and adulthood.

In the Philippines, ADHD is recognised by the government as one of the categories in developmental disabilities, and an official ADHD awareness week (supported by the government) has been practiced. Since 2020, the ADHD Society of the Philippines, a nonprofit organisation dedicated to supporting individuals with Attention Deficit/Hyperactivity Disorder (ADHD), has been established. The initiative began as a parent-based group, and has since evolved into a diverse and balanced representation of members, including medical practitioners, academicians, special education (SPED) professionals, parents, and adults with ADHD. The organisation's mission is to promote the well-being of individuals with ADHD through various programmes, projects, and activities. One of their ongoing programmes is to promote neurodiversity within higher education (<https://www.adhdsocphils.org/>).

In November 1997, The Philippine Dyslexia Foundation (PDF) was established as a nonprofit organisation by parents and teachers of children with dyslexia and other related learning difficulties. Dyslexia is a learning disability in reading that primarily affects the skills involved in accurate and fluent word reading and spelling. Some characteristics of dyslexia include difficulties in phonological awareness, verbal memory, and verbal processing speed (British Dyslexia Association, 2010). The PDF is actively involved in promoting public awareness about dyslexia and provides programmes such as literacy assessment, after-school programmes for children with specific learning needs, and training sessions for parents and teachers through seminars and workshops, (<https://philippinedyslexiafoundation.org/>).

Source: Compiled by authors (2023).

## 4.4 Community life, group home, and funding support

### *Group home and community living*

Providing living places in community settings with extensive support for persons with developmental disorders will be beneficial in offering more opportunities for social inclusion. Previously, many individuals with severe developmental and intellectual disorders lived in segregated institutions and residential settings that limited their participation in society and hindered their ability to exercise control over their lives (Esteban et al., 2021). This practice is not in compliance with the principles of non-discrimination, equal opportunities, and accessibility stated in the United Nations Convention on the Rights of Persons with Disabilities, which aims to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all PWDs through appropriate modifications and adjustments (Esteban et al., 2021).

A number of benefits provide community living and group home for persons with developmental disorders. Our key informants from Indonesia (families with and practitioners in developmental disabilities) discussed their opinions on the opportunities and challenges for providing these facilities:

- **Independence is a primary goal** for persons with developmental disorders, especially during the transition from adolescence to adulthood. Regrettably, not everyone has access to suitable accommodations, including housing facilities, environments, and essential resources necessary to support individuals with developmental disorders in living independently.
- Group homes as learning independence. In 2022, group home facilities were introduced by the partners in Japan. Group homes can be utilised as a tool and a place to learn how to live independently, especially for individuals with developmental disabilities, including those with autism, particularly during their young age until they reach adulthood as job seekers.
- Group homes and training. The group home could initiate programmes such as training to develop independence, self-care skills, group work, socialisation, and improvement of communication and working skills.
- Support for people with no family. The group home could serve as a house for persons with developmental disorders who no longer have parents or who choose to live separately from their parents. This is considering that **the group home can provide and accommodate proper facilities for persons with developmental disorders.**
- Funding. The biggest obstacle is funding, due to the necessity of providing facilities such as buildings, the high cost of operational budgets, maintenance, and hiring a professional team. A significant amount of funds and qualified human resources are required.
- Limited by size. Compared to a special needs school, where one building can accommodate many students, a group home can only provide for a limited number of individuals. For example, (a maximum of) 4 to 6 individuals can live together. Therefore, a sound financial model for providing economic value in group homes is needed.

### Box 6: Opportunities and Challenges in Establishing a Group Home: Indonesia and Viet Nam

In Indonesia, one of the key informants for this study, Taufiq Hidayat from Yayasan Autisma Indonesia (Indonesian Autism Foundation), once planned to establish a sheltered workshop but later he considered developing a group home. Despite the potential benefits of establishing a group home for individuals with autism to promote better independent living skills and greater community participation, several challenges required a great investment, such as:

- The high cost of building the facilities. The estimated cost for renting and renovating the place in 2023 is at least Rp 475 million or equal to ¥4,3 million.
- The operational cost. Each facility requires a minimum of four caregivers for daily operation. Considering the minimum wage in the Jakarta region, the salary for each person working for 8 hours/day is equal to Rp 4,5 million or ¥39,800 (as of 2023).
- There is also a need to recruit a programme manager for developing and conducting vocational programs and independent living skill learning programs. A program manager's salary is approximately Rp 11 million or ¥97,000 per month (as of 2023).
- For the residents who require therapy sessions, there is a cost to hire a part-time therapist as occupational therapist, physiotherapist, and speech therapist which cost Rp 500,000 or equal to ¥450 per visit (per person).

In Viet Nam, a group home project for autistic adults is being developed in 2023, namely, Bao Loc group home. The facility is currently under construction and will be operating in March 2024 (according to interview data in 2023). Initiated by a group of parents with autistic children from VAN, this project follows their previous initiative in 2008 – building the Tuoi Ngoc Special School in Ho Chi Minh City for their children to study and foster social interactions with their friends.

As the children have grown up, there is a need to provide a place where they can learn and practice independent living skills. After joining the Japan Roundtable Discussion in March 2023 – where the group home project for persons with developmental disorders in Japan was introduced – the Bao Loc group home project was developed. Situated in Bao Loc province (approximately a 4-hour drive from Ho Chi Minh City), the facilities are designed to cater to around 10 individuals with autism, both young and adult. According to VAN chairperson Pham Thi Kim Tam, the group home project is designed to open an early intervention programme for younger children and will accept two to three individuals with autism for reintegration into the community each year. For teenagers and adults with autism, classes are provided to develop life skills, self-care skills, and handicraft skills.

A daily schedule, including exercise and sport sessions, group work sessions, study sessions, and daily activities, has been developed for the residents of the group home. Some important issues have been considered regarding the operation and maintenance of the facilities, including the possibilities of using inheritance law to finance the cost of living for group home's residents. Inheritance law in Viet Nam recognises the inheritance rights of people with intellectual disabilities but requires a guardian to manage inherited assets. Guardians are usually parents, siblings, or family members. However, the law does not specifically mention the mechanism for supervising the guardian to ensure the rights of the heir, who is intellectually disabled.

Source: Compiled from interviews (2023).

### *Funding and allowance support*

There are several funding and allowance support for persons with developmental disabilities in ASEAN countries. Although not all countries have such programmes, most disability allowances are targeted at poor families to facilitate access to healthcare, education, and social welfare support. The majority of funding programmes are provided by the state as part of financial assistance for PWDs, including those with developmental disabilities and mental health issues. Below are some examples of funding and allowance support provided by the government and NGOs in ASEAN.

**Table 4.1: Examples of Funding and Allowance Support Available for Persons with Developmental Disorders in ASEAN Countries**

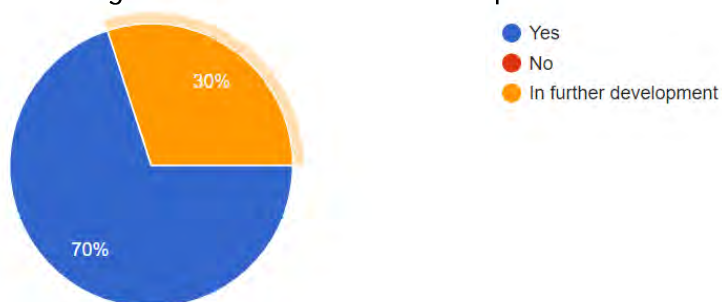
Countries	Examples of Funding and Allowance Support	Provided by
Brunei Darussalam	Disability allowance and mental disorder allowance	Government (Social welfare)
Cambodia	Free intervention/treatment programme for poor families	Government and NGO
Indonesia	<ul style="list-style-type: none"><li>- Social assistance through Hope Family programme</li><li>- Social rehabilitation programme</li><li>- Educational fund through Kartu Indonesia Pintar programme (for poor families)</li></ul>	Government (Ministry of Social Affairs, Ministry of Education)
Malaysia	(Disability) allowance	Government (Social welfare)
Myanmar	One-time fund/cash support during COVID 19 pandemic period	Government
Singapore	<ul style="list-style-type: none"><li>- Employment support for persons with disabilities</li><li>- Lifelong Learning Enabling Fund</li><li>- Home Caregiving Grant</li></ul>	Government and appointed agencies
Philippines	<ul style="list-style-type: none"><li>- Modified Conditional Cash Transfer Programme (for those who are categorised in low socioeconomic status)</li><li>- Disability allowance and discount programs for PWDs, including developmental disabilities</li></ul>	Government
Viet Nam	Pension and social welfare support for PWDs	Government

Source: Interview data and other resources (2023).

#### 4.5 Judicial procedure and decision-making support

People with intellectual and developmental disorders are overrepresented in the criminal justice system and judicial procedures as victims, witnesses, suspects, and defendants. To ensure that they can get equal access to judicial proceedings and services, and that their unique needs are considered in decision-making processes, it is essential to establish a legal framework and enact comprehensive legislation. In most AMS, there is awareness of the need to avoid discrimination against persons with developmental disorders, including in judicial procedures, as seen in Figure 4.1.

**Figure 4.1: Prohibition for Governments, Public institutions, and Companies to Discriminate against Persons with Developmental Disorders**



Source: Questionnaire data (2023).

In Indonesia, for example, under Government Regulation No. 39 of 2020, the state has committed to provide adequate accommodation for PWDs in judicial proceedings. However, supporting judicial procedures for persons with developmental disorders requires a long process to identify their needs, provide accessibility accommodations during trials, and build the capacity of the justice system to address the legal needs of PWDs (Open Government Partnership, 2022). There is still much to be done to develop technical regulations that not only focus primarily on services, facilities, and infrastructure but also provide procedural steps to ensure the fulfillment of rights and obligations for PWDs (Open Government Partnership, 2022).

Another important issue is to provide decision-making support for persons with developmental disorders. They may need assistance in making decisions about living arrangements, healthcare, relationships, and financial matters. In particular, when they are entering adulthood, persons with developmental disorders may need assistance to make their own decisions.

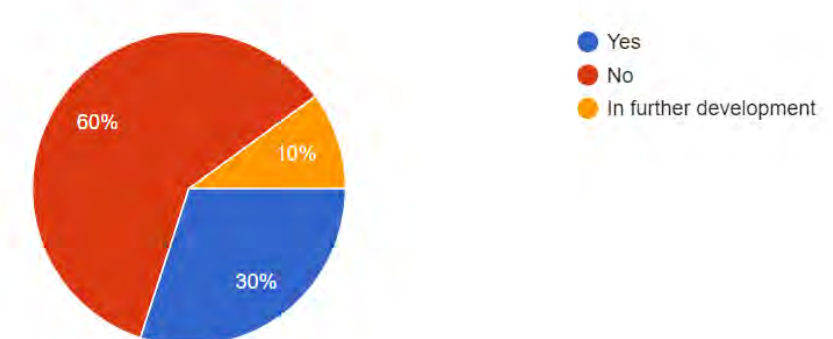
Supported Decision-Making (SDM) is an approach empowering individuals with disabilities to make their own choices with the help of a team of people they choose (ACL, 2023). This approach is an alternative to guardianship. They can select trusted individuals, including family members, co-workers, friends, and past or present providers, to form a support network aiding in decision-making. Some countries,



including the US, Sweden, Norway, and Ireland, have promoted a system and regulations to allow PWDs to make decisions on various issues.

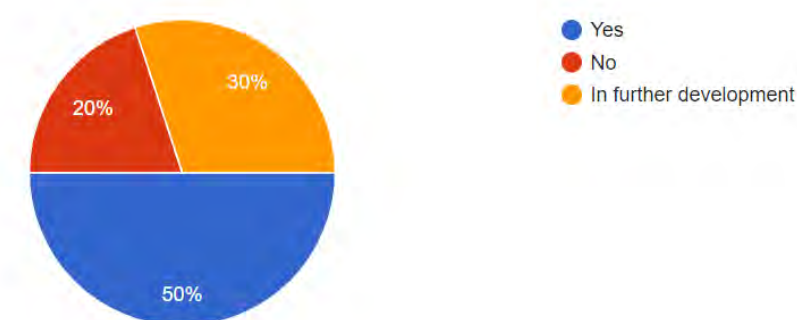
Several prerequisites are essential for implementing this approach, including establishing a support team, developing decision-making skills for those with developmental disorders, creating a legal framework, and ensuring resource availability. According to our survey results (see Figures 4.2 and 4.3), most ASEAN countries need to prepare resources for supporting persons with developmental disorders. This includes training professional human resources related to services for supporting individuals with developmental disorders.

Figure 4.2: Supported Decision-making for Persons with Developmental Disorders



Source: Questionnaire data (2023).

Figure 4.3: Human Resources Training Programmes from the Government



Source: Questionnaire data (2023).

Developing professional human resources to support individuals with developmental disabilities involves several aspects, such as creating an inclusive environment, establishing support systems, and adhering to state and federal guidelines. Training programmes are essential to equipping professional human resources with specific skills. For example, training sessions on disability awareness and inclusion are crucial. This may encompass training on accessibility and accommodations for persons with developmental disorders, teaching effective communication strategies, and providing an understanding of legal frameworks related to disability rights.

#### 4.6 Disaster mitigation and crisis support

Disasters, regardless of their scale, present challenging situations for persons with developmental disorders. Due to the varying degrees of conditions, individuals with developmental disorders need different access and accommodations during disasters. However, emergency responders and officials should adopt some universal considerations – regardless of circumstances and available resources – to ensure all members of the community can be properly supported during the stages of pre-disaster and post-disaster (SAMHSA-DTAC, 2024).

During the preparation stage, communication planning must be provided in accessible ways, including drafted announcements, warnings, and instructions. Community outreach and education can be achieved by utilising media campaigns, digital platforms, and partnering with local or regional disability organisations (SAMHSA-DTAC, 2024). Efforts to support the disaster-related needs of people with developmental disabilities should also focus on long-term risk reduction, as this can enhance community resilience (FEMA, 2021).

The ASEAN Enabling Masterplan 2025 suggests developing ‘disability-inclusive disaster resilience plans in consultation with organisations of persons with disabilities and persons with disabilities’ (ASEAN, 2019). Further recommendations also include establishing a network of disability and human rights professionals and consulting the network of organisations of PWDs in the planning, implementation, and evaluation of policies and programmes on disaster and emergency preparedness (ASEAN, 2019).

Some countries in ASEAN have prepared emergency plans, including establishing lists of residents in need of assistance in evacuation to ensure a smooth and prompt evacuation during disasters (Interview data, 2023). For example, the Philippine government established the Centre for Disaster Preparedness. As a country with a high risk of disasters, they acknowledge the need to set up a centre specialising in implementing humanity and inclusion principles, conducting training and advocacy for disability inclusion in the Disaster Risk Management Framework (see Chapter 2).

Others rely on collaborations between government agencies, NGOs, and disability organizations to provide support for persons with disabilities, including those with developmental disorders in times of disaster or crisis. However, some countries have not yet included persons with developmental disabilities in disaster preparation or plans (Interview data, 2023).

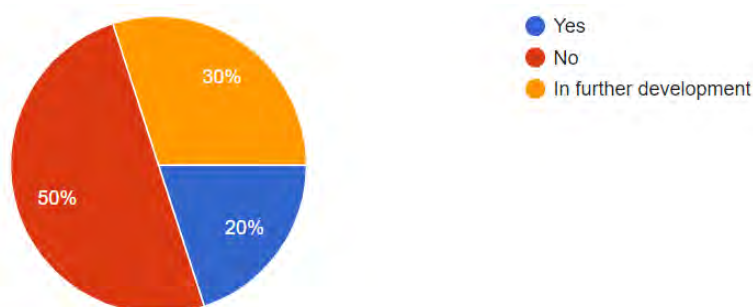
#### 4.7 Research on developmental disorders

Researcher plays a critical role in generating scientific evidence, which is crucial for shaping policies, practices, and public awareness regarding existing disparities (Zakirova-Engstrand and Yakubova, 2023; Mir et al., 2012). However, research related with autism and developmental disabilities in low- and middle-income countries is

considered insufficient compared to high-income countries (Zakirova-Engstrand and Yakubova, 2023). Despite the paucity of research in developmental disorders in ASEAN countries, such research has been conducted by government agencies, academic institutions, and research organisations to identify knowledge gaps and research priorities (See Figure 4.4. The areas explored in the research mainly focus on intervention and rehabilitation, special education, and autism and intellectual disabilities (Interview data, 2023). However, a limited number of research publications address the needs of individuals with developmental disorders, their families, and professionals in the region.

According to previous studies in non-Western countries, awareness about autism – as one of the developmental disorders – remains low amongst the general public and healthcare professionals (Abubakar et al., 2016; Habib et al., 2017; Zakirova-Engstrand and Yakubova, 2023). Low awareness and a lack of understanding about developmental disabilities could lead to social stigma, discrimination, and exclusion experienced by individuals with developmental disabilities and their families in their everyday lives (de Leeuw, Happé, and Hoekstra, 2020; Zakirova-Engstrand and Yakubova, 2023). Increasing awareness about developmental disorders amongst the general public and conducting more research in that area could support a stronger knowledge base for scholars and professionals. It could also foster greater acceptance towards persons with developmental disorders and their families, ultimately contributing to their health and well-being (Zakirova-Engstrand and Yakubova, 2023).

Figure 4.4 Research Conducted by the Government on Developmental Disorders



Source: Questionnaire data (2023).

Previous studies on priorities for autism research in Asia suggested some important areas should be developed, as they would have a greater impact on the everyday lives of individuals with autism. This includes the development of effective interventions, improvement of access to services, and increased awareness of autism (Zakirova-Engstrand and Yakubova, 2023). Besides, there is a need to involve more members of autistic communities and individuals with autism to promote greater inclusivity in research, gain deeper insights, and better identify the needs of persons with autism.

### **Box 7: IDD Net and Research Priorities for Developmental Disorders**

In the course of this project, an initiative was established to enhance the support and understanding of developmental disorders in Indonesia. The initiative, the Indonesia Developmental Disorder Network (IDD Net) was launched on 31 August 2023. It is based on one of the recommendations from the Japan–Indonesia Roundtable Discussion on Developmental Disorders held in Tokyo, 8 March 2023. IDD Net drew inspiration from the Japan Developmental Disorder Network as a model for its establishment and development.

The network is expected to serve as a hub incorporating national and local organisations for people with developmental disabilities, parent associations, academic societies, research groups, and professional organisations related to developmental disorders. As a national network representing developmental disorders in Indonesia, this organisation aims to support persons with developmental disorders, including autism, ADHD, learning disabilities such as dyslexia, and other developmental disorders. These individuals may currently be part of the conventional system and are not yet eligible for support or have not received proper support.

As a forum for advocating the rights and interests of people with developmental disabilities, IDD Net is expected to provide understanding through research and policy proposals. It also aims to advocate for policy changes that support people with developmental disabilities. One agenda item is to promote context-specific and interdisciplinary research on developmental disorders, including early interventions, family support, health access and communication, and technologies to support persons with developmental disorders in Indonesia.

Source: Compiled by authors (2023).

# Chapter 5

## Comparative Study on Policies in Indonesia, the Philippines, Viet Nam, and Japan

### 5.1 Japan

Japan has implemented a comprehensive law addressing the well-being of both mothers and children, established by the Ministry of Health, Labour and Welfare (MHLW) in 1965 – the Maternal and Child Health Law. This legislation mandates regular paediatric health examinations for every child in Japan, conducted by the local municipality. In addition to this, the Act on Support for Persons with Development Disorders introduces an additional layer of obligation, emphasising the early identification of potential developmental disorders. For instance, in the case of autism, early detection involves using the Modified Checklist for Autism in Toddlers at 18 months of age to assess social development. At 36 months old, observations during group activities serve to identify potential indicators of ASD or ADHD. Moreover, before a child enters elementary school, health examinations are conducted to detect issues such as stuttering, tics, reading and writing difficulties, as well as motor skill problems.

Other than that, parents are also encouraged to record their child's developmental progress in the maternal and child handbook, issued by the local municipality. This handbook serves as a valuable tool for monitoring growth and development. Additionally, parents can consult medical and healthcare institutions if any concerns arise. These tools and practices were developed by the National Centre for Neurology and Psychiatry through research initiatives facilitated by the MHLW. Maternal and child handbooks are produced through a collaborative effort between the MHLW and local municipal governments. While the ministry establishes standardised formats, individual municipal governments design the covers with their original artworks. The contents of these handbooks include prenatal health records, growth curves, schedules for infant and toddler health check-ups, as well as records from these examinations. This book forms a comprehensive resource for monitoring and documenting the health and development of both mothers and children.

Parents of children who show indications of potential developmental disorders can engage in various supportive activities and access resources provided by their local municipal governments. These include individual consultations and group discussions, participation in specialised parent training led by experts such as psychologists and childcare specialists, as well as seeking advice from parent mentors with experience in caring for children with developmental disorders. The process to recognise the possibility of a disorder can take time due to individual circumstances within the family and

household. The process can involve various steps, such as seeking a medical diagnosis, undergoing rehabilitation from professionals like occupational therapists and speech therapists, and accessing child development support centres operated by local governments or private entities before diagnosis. These centres facilitate activities and programmes to aid in a child's development.

However, the decision of when to initiate these steps and which services to utilise, as well as the frequency of their use, depends on the parents. They have the agency to make these choices based on their child's needs and circumstances. Recently, there has been growing concern regarding the declining quality of services in some establishments. This highlights new issues that require attention in the context of accessing and utilising development support services.

In Japan, special need education is divided into four categories: the kindergarten course (1–6 years old), elementary school course (6–12 years old), junior high school course (12–15 years old), and high school course (15–18 years old). Compulsory education is from elementary to junior high school. Classes for special needs education are available from elementary to junior high school, and special needs services in resource rooms are available from elementary to high school. An overview of special needs education for developmental disorders in Japan is elaborated in Table 5.1.

**Table 5.1: Overview of Special Needs Education and the Number of Enrolled Students with Developmental Disorders**

		Special Needs Education School	Special Needs Classes	Special Support Services in Resource Room
Disabilities Type	Intellectual disabilities	0 137,801 students	0 156,661 students	-
	Speech & language disorders	-	0 1,331 students	0 43,630 students
	Autism or emotional disturbance	-	0 183,618 students	0 21,837 students 32,347 students of High-Functioning Autism
	Learning disabilities	-	-	0 30,612 students
	Attention deficit / Hyperactivity	-	-	0 33,827 students
Total Students		137,801	340,601	165,253
Number of Schools		1,200	25,000	Mainstream school

Class Design	Elementary–Junior high: 6 students per classes Senior high: 8 students per classes	8 students per classes	Elementary–Junior High: 1 teacher for every 13 students High School: additional assignment
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Note: Students with multiple disabilities have been compiled for each disability type.

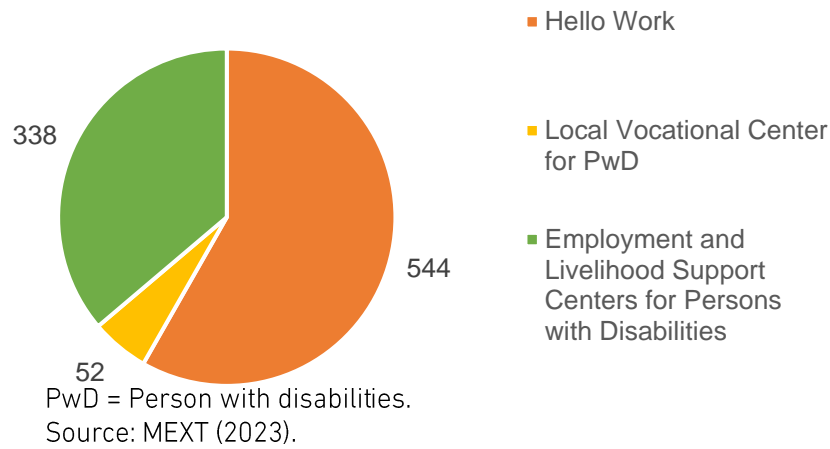
Source: Ministry of Education, Culture, Sports, Science and Technology of Japan (MEXT) (2023).

Table 5.1 shows the options available to parents, guardians, and children with developmental disorders. They can choose which schools and learning methods are suitable for children's education. Both parents or guardians and schools can engage in consultations to develop an 'individual instruction plan' and 'individual educational support plan'. Additionally, several adjustments are available based on the individual characteristics of students with developmental disorders in both high schools and universities. However, the options available for those with learning disorders and ADHD are still limited as no special need schools and classes are available. This underlines the need for further attention and initiatives to address the unique learning requirements of individuals with learning disorders and ADHD in the educational system.

Students with developmental disorders who aspire to participate in entrance exams for high schools and universities can request reasonable accommodations, such as taking the exam in separate rooms and receiving enlarged printouts. Furthermore, after school hours, children with developmental disorders can request day services during long holidays. Persons with developmental disorders and/or their parents or guardians also can opt to provide consent for sharing personal information with the government, schools, hospitals, and others supporting organisations.

Japan also has family support systems in place for individuals with developmental disorders. Families can request additional assistance from experts and receive mutual support from other family members through initiatives like the Peer Support Promotion Project. In this project, local municipalities gather individuals facing similar challenges or children with developmental disorders and provide temporary care for the children. Moreover, if family members encounter difficulties in managing the situation on their own, they can seek assistance through home-visit nursing care (support for nursing care and housework by non-family members), short-term admission, and temporary daytime support (on behalf of the person concerned).

Figure 5.1: Number of Employment Support Centres for Persons with Developmental Disorders

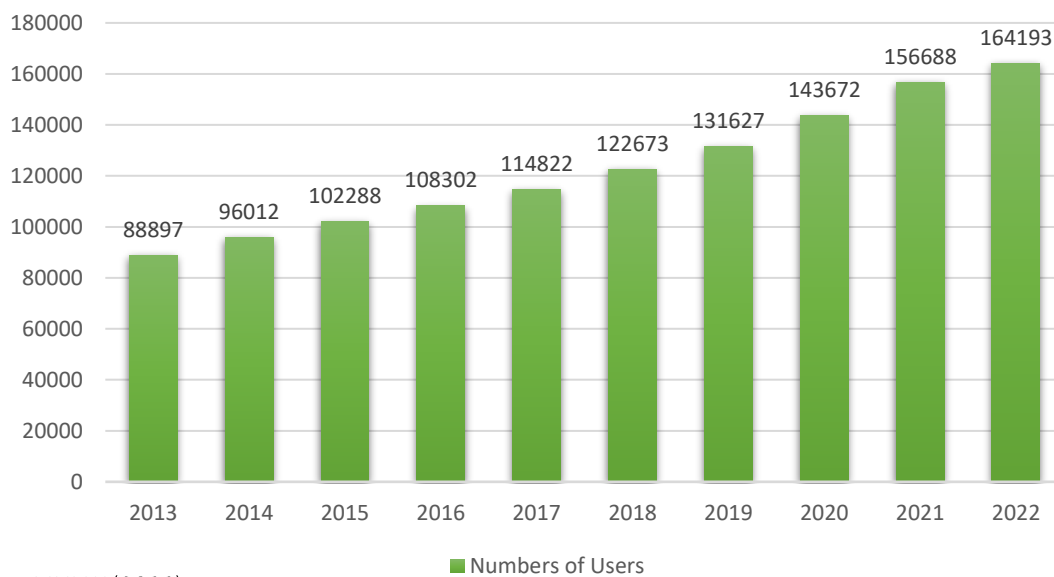


Persons with developmental disorders in Japan can receive employment support from various organisations. Firstly, the public employment security offices operate 'Hello Work', an employment service centre that offers job placement, vocational guidance, and the development of job opportunities for individuals with developmental disorders. Secondly, the Japan Organization for Employment of the Elderly, Persons with Disabilities and Job Seekers manages local vocational centres for persons with disabilities, which employ full-time counsellors to provide career assessments, preliminary training, and job coaching for those with developmental disorders. Thirdly, employment and livelihood support centres for persons with disabilities are managed by social welfare corporations and NGOs, designated by prefectural governors. These centres provide integrated consulting and support for employment and livelihood at the local level.

Furthermore, support for community life is also available for persons with developmental disorders in Japan. There are 12,068 group homes established, providing a place for PwDs, including those with developmental disorders, to live together in a family-like atmosphere within an area where interaction with residents is secured (MHLW, 2023). Group homes offer various services, primarily during the night, such as housing consultations, nursing care for bathing, excretion, meals, as well as daytime activity services, coordination, and liaison with the person's place of employment, and leisure activities. Individuals with developmental disorders can use group home facilities for short-term admissions, and both home visits and ICT-based consultations are also available upon the person's request. Figure 5.2 outlines the growth of group home users.



Figure 5.2: Growth of Group Home Users from 2013 to 2022



Source: MHLW (2023).

In terms of advocating for persons with developmental disorders, the MHLW and MEXT introduced the Partial Revision of the Act on Support for Persons with Development Disorders (2016) as a comprehensive update to enhance assistance for individuals with developmental disorders. This legislation is designed to eliminate discrimination and prevent abuses in schools and workplaces. Schools are mandated to implement individualised educational support, guidance plans, and measures to prevent bullying. Furthermore, companies are obliged to hire a specified number of individuals with physical/intellectual/psychosocial disabilities. This obligation is enforced through the collection of levies from companies that do not meet their designated employment rate, and subsidies are provided for those who successfully employ a considerable number of individuals with disabilities. The mechanism is outlined as follows:

- Levies for around US\$340 per month per person for companies that do not meet their employment rate quota.
- Subsidies of around US\$184 per month per person for companies that successfully meet their employment rate quota.
- Subsidies will be adjusted for companies that employ individuals with disabilities in home-based work.
- Subsidies are granted for facilities and caregivers required to employ individuals with disabilities.

Companies are also obliged to prohibit discrimination against persons with developmental disorders and have duties to provide reasonable considerations as follows:

- Discriminatory treatment in employment due to disabilities is strictly prohibited.

- Employers are obliged to take necessary measures to eliminate any obstacles in the workplace where individuals with disabilities work unless such measures impose an undue burden on the employers.
- Employers are obliged to exert proactive efforts to address any complaints from individuals with disabilities regarding the prohibition of discrimination and the duty to provide reasonable accommodations.

Furthermore, the Partial Revision of the Act on Support for Persons with Development Disorders has introduced regulations regarding adult guardianship. This system is designed to protect and support individuals who lack the capacity for judgement in a normal state due to mental disorders such as dementia, intellectual disabilities, psychosocial disabilities, and so on. When this system is utilised, adult guardians appointed by the family court act on behalf of the person, performing legal acts such as contracts while considering the person's interests. The person or adult guardian may also later rescind unfavourable legal actions performed by the person lacking capacity (Ministry of Justice, 2016). There are three categories of adult guardianship – guardianship, curatorship, and assistance – which are classified based on the degree of the person's capacity for judgement. However, activities related to daily life are excluded. More details about adult guardianship are provided in Table 5.2.

**Table 5.2: Adult Guardianship Features**

	<b>Guardianship</b>	<b>Curatorship</b>	<b>Assistance</b>
Target	Those who constantly lack capacity for judgement in normal state	Those who have significantly insufficient capacity	Those who have insufficient capacity for judgement
Acts that adult guardians can agree or cancel	In principle, all legal acts	Acts stipulated in Article 13, paragraph 1 of the Civil Code (See Notes 2 and 3)	Specific legal acts specified by the family court at a hearing within the scope of the petition (See Notes 1 and 2)
Acts that adult guardians can perform on the ward's behalf	All legal acts concerning property	Specific legal acts specified by the family court at a hearing within the scope of the petition (Note 1)	Specific legal acts specified by the family court at a hearing within the scope of the petition (Note 1)
Those who can make petition	The person in question, his/her spouse, relatives within the fourth degree of kinship, or public prosecutor. Heads of municipalities (Note 1)		
Additional Notes	1. The consent of the person under curatorship will be required if the request is made by others to give a curator specific		

	<p>legal authority. The same is true for hearings giving the right of consent or specific legal authority to an assistant and hearings to start assistance.</p> <ol style="list-style-type: none"> <li>2. Article 13, paragraph 1 of the Civil Code states actions such as debt, litigation, approval and abandonment of inheritance, new construction, reconstruction, and extensions.</li> <li>3. Through hearings in family court, the scope of the right of consent and the right of cancellation can be extended in addition to the acts prescribed in Article 13, paragraph 1 of the Civil Code.</li> </ol>
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Source: Ministry of Justice of Japan (2016).

Police, prosecutors, and court officials in Japan can also receive support based on their disability characteristics during the judicial proceeding process. Several accommodations and considerations are available, including the provision of interpreters, communication aids, and adjustments to the courtroom environment to suit the individual's needs. In some cases, a welfare commissioner may be appointed to represent the interests of individuals with developmental disorders in legal matters. This is particularly relevant in cases involving criminal proceedings or when the person's legal capacity is significantly restricted. After individuals with developmental disorders leave the correctional facilities, they can request consultation and support regarding community life.

Support centres for persons with developmental disorders are available in each prefecture. These centres are operated by local governments and provide various resources, assistance, and support for individuals and their families. Specifically, these centres are assigned to perform several tasks:

- Transmission of local information that can be easily accessed by persons with developmental disorders as well as their families;
- Consultation support regarding health, livelihood, available programmes and resources, employment, education, training, assertive device, etc.;
- Human resources development to maintain a pool of workers specialised in developmental disorders.

In addition, researchers continuously conduct research on developmental disorders in Japan, specifically within the scope of implementation. These research efforts primarily focus on early intervention and screening, educational intervention, assertive devices, improvement of social inclusion, transitions to adulthood, ensuring mental health and well-being, family and caregiver support and well-being, as well as improvements in current policies and available services.

## 5.2. Indonesia

Indonesia and Japan implement similar systems and policies regarding early detection and intervention for developmental disorders. The process in both countries targets children aged 0–6 years, utilising books for parents to document their children's development (referred to as *Buku KIA* or *Buku Kesehatan Ibu dan Anak* in Indonesia). Indonesia ensures the accessibility of early detection and intervention through the availability of primary healthcare services, such as *Posyandu* (integrated health post) and *Puskesmas* (community health centre), which are widely distributed throughout the country. These facilities serve as primary points of contact for individuals seeking basic medical services, health promotion, disease prevention, maternal and child health, as well as mandatory immunisation. They play a crucial role in providing stimulation, detection, and early intervention for developmental disorders.

There are also similarities between the mechanisms of Indonesia and Japan in conducting stimulation, detection, and intervention for developmental disorders. Both countries have implemented the Modified Checklist for Autism in Toddlers to detect autism in toddlers. In Indonesia, the MOH also implemented its regulation in 2016, the *Kuisisioner Masalah Perilaku Emosional* (Emotional Behavioural Problems Questionnaire – KMPE). This questionnaire is conducted every 6 months for children aged 36–72 months. Furthermore, the Form of *Gangguan Pusat Perhatian dan Hiperaktivitas* (ADHD) is conducted once healthcare officers receive reports from parents or preliminary schoolteachers to detect children older than 36 months.

However, while Japan has child consultation centres serving as central hubs that offer support to children with developmental disorders and their families, Indonesia mostly relies on non-governmental organisations for specific support tailored to children with developmental disorders. In Indonesia, most support is provided in primary healthcare facilities. Parents or guardians can request additional assistance, such as further coaching, from several NGOs. One of the most reputable organisations providing coaching for parents is Autism Recovery Network, where parents are trained in Applied Behaviour Analysis to guide them during the intervention phase for children with autism. Additionally, there are no childcare facilities specialised for children with developmental disorders in Indonesia. As a result, parents or guardians often must recruit childcare workers and directly trained them to understand the treatments for their children.

Both Indonesia and Japan also have regulations to ensure education for children with developmental disorders. Law No. 8/2016, ratified by the Indonesian government in 2016, ensures that persons with disabilities have equal access to education and receive the necessary accommodations and support to enable them to learn and develop their skills. This law was further implemented through the publication of *Buku Saku Penyelenggaraan Pendidikan Inklusif di Sekolah Dasar* (Handbook for the Implementation of Inclusive Education in Elementary Schools) by the Directorate of Elementary School in 2021 to ensure that children with developmental disorders can receive proper methods according to their needs. This handbook comprises several aspects, including:

- Identification, assessment, and consultations for school and learning methods in both special needs and regular schools
- Education considerations and academic adjustments, such as a guide to establishing an individual education programme based on the individual characteristics of students with developmental disorders
- Availability of academic support through the *Unit Layanan Disabilitas* (Disabilities Service Centre) at both the primary education and university levels
- Establishment of a resource centre as an independent organisation focusing on providing guidance and support for educational institutions facing issues in inclusive education development

Students with developmental disorders can also participate in various after-school activities upon their request to specific organisations that provide training and support for them outside of school. These supports include training for social skills and cognitive abilities, extracurricular activities, as well as *Kelompok Bermain Terpadu* (playgroup) for children under 6 years old. These policies are fundamentally like those in Japan, where parents or guardians, along with children with developmental disorders, can choose schools and learning methods that best suit the student's characteristics. However, the main difference lies in the availability of schools/classes/resource rooms for developmental disorders. Efendi (2018) highlighted that Indonesia is still lacking in the preparedness of the recommended schools to provide adequate learning facilities and resource support for students with developmental disorders.

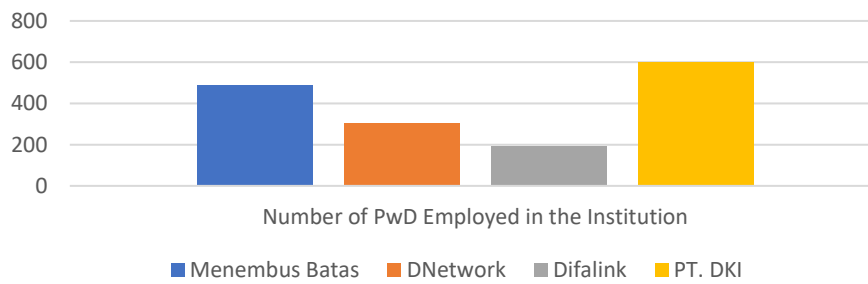
Similarities between Japan and Indonesia lie in the regulation of information sharing concerning personal information, including those with developmental disorders. In both countries, personal information of individuals with developmental disorders can be shared amongst government institutions, schools, hospitals, and other supporting organisations, if legal consent from the owner is obtained. The Government of Indonesia (Ministry of Communication and Informatics, 2022) governs this mechanism through Law No. 27/2022 on Personal Data Protection. The utilisation of personal data for commercial purposes is strictly regulated, thereby helping prevent the misuse of personal data and protect the privacy right of individuals with developmental disorders.

Both Indonesia and Japan have government-based employment support institutions for persons with developmental disorders. In Indonesia, the government has established *Balai Latihan Kerja* (BLK) or Vocational Training Centre); some city branches already pursuing inclusive BLK. In terms of NGOs, Indonesia has several that focus on employment support, such as:

- Menembus Batas, which offers vocational training programmes in cleaning, massage therapy, and car washing

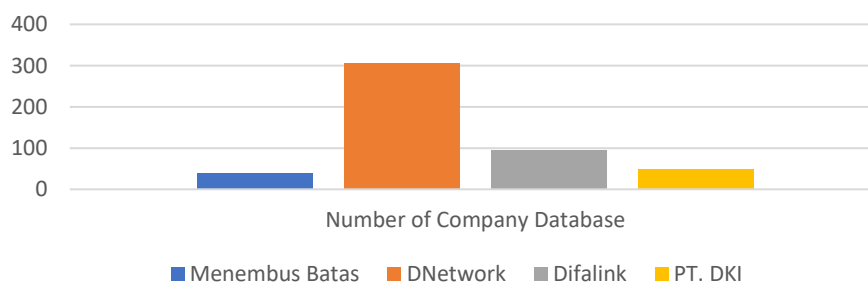
- DNetwork, which provides job portals, various training programmes in the private and public sectors, as well as conferences for employers to enhance inclusivity within the workplace
- Difalink, which utilises job portals and manages Disabilities Empowerment for Professional Equality focusing on digital skills, Disabilities to the Next Abilities concentrating on soft skills towards the end of primary education, and Disabilities Empowerment for Hospitality Focused concentrating on the hotelier industry
- PT. Disabilitas Kerja Indonesia, which aims to connect job seekers with employers, providing training to prepare job seekers for work and enhancing organisational readiness for companies.

Figure 5.3: Number of Persons with Disabilities Employed in NGOs in Indonesia



Source: Collected from the official website of the mentioned institutions.

Figure 5.4: Company Database from NGOs in Indonesia



Source: Collected from the official website of the mentioned institutions.

However, while persons with developmental disorders in Japan can choose vocational training based on their skills, preferences, and conditions, the situation in Indonesia is different in most cases. Only a limited number of institutions offer various options for vocational training, and the majority focus on labour vocational training, such as cleaning, massage therapy, and car washing. On the positive side, NGOs in Indonesia have programmes aimed at enhancing companies' readiness and inclusivity through organisational training and collaboration in recruitment and talent development.

Moreover, these organisations also support and accommodate job seekers with disabilities, including those with developmental disorders, providing consultation on job hunting and addressing adjustment requests within the workplace once they are recruited. In most cases, the recruitment of workers with disabilities is conducted on a separate time frame from general employment.

In terms of community life support, while Japan focuses on daily activities, outings, pensions, and discounts, Indonesia places a greater emphasis on conditional cash transfer policies and universal health insurance. According to Larasati et al. (2019), the Indonesian government partially covers the needs of PWDs through *Program Keluarga Harapan* (Hope Family Program) providing conditional cash transfers to poor households, including those with family members with developmental disorders. Additionally, the *Asistensi Sosial Penyandang Disabilitas Berat* (Social Assistance Program for Severe Disabilities) offers conditional cash transfers to individuals with severe disabilities. The *Jaminan Kesehatan Nasional – Penerima Bantuan Iuran* (National Health Insurance – Premium Assistance Recipients) aims to provide affordable and accessible healthcare services to all Indonesian citizens. The term 'premium assistance recipients' refers to individuals or households receiving financial assistance to cover their health insurance premiums.

However, Indonesia is beginning to regulate the discount benefits for PWDs, including those with developmental disorders. This is similar to Japan, which provides multiple discounts for PWDs in various public facilities, shopping, and entertainment venues. In Indonesia, the official identification for PWDs started in Jakarta (Indonesia's capital city) with the initiative to establish the *Kartu Penyandang Disabilitas Jakarta* (Jakarta Disabilities Card Identification) in 2019. This card provides benefits and services, including social assistance from the government, such as disabilities pensions, education assistance, and job training. Additionally, it offers discounts and special facilities in various public places, such as public transportation, tourist attractions, and entertainment venues. In 2021, the Ministry of Social Affairs ratified *Permensos No. 2/2021* to expand the scope of the Disabilities Card Identification to the national scale. However, the regulation is considered new and will take some time to be fully implemented nationwide in Indonesia.

Furthermore, while Japan has group home facilities for individuals with developmental disorders, Indonesia offers limited support for those facing similar challenges in terms of daily activities, housing, and community social gatherings. In Indonesia, most community-based facilities take the form of rehabilitation camps, which often segregate persons with developmental disorders from the general community, rather than helping them integrate into a broader environment. In addition, these rehabilitation camps are primarily NGOs and religious institutions. In many cases, parents or guardians of individuals with developmental disorders choose to place their children in these facilities due to limited resources and the inability to ensure their children receive proper education and support.

Both Japan and Indonesia advocate against bullying, especially targeting children with developmental disorders. In both countries, schools are required to promote individualised educational support, guidance plans, and measures to prevent bullying. In Indonesia, the Ministry of Education, Culture, Research and Technology regulates this obligation through the 2015 ratification of *Perkemendikbud* No. 82/2015, which addresses the prevention and management of acts of violence in the education unit environment. This regulation includes preventive actions, countermeasures to handle violence in education units, and legal punishments for the perpetrators of violence. However, these regulations apply to all students and are not specifically tailored for those with developmental disorders.

Furthermore, both Japan and Indonesia have regulations regarding the rights of persons with disabilities to work and access equal opportunities in the labour market without discrimination. However, while Japan has the Partial Revision of Act on Support for Persons with Development Disorders, which specifically addresses the rights of persons with developmental disorders, Indonesia has a general law to ensure the rights of all kinds of disabilities in Law No. 8/2016. This law prohibits employers in the public and private sectors from discriminating against PWDs and requires employers to treat PWDs equally, providing necessary adjustments based on their needs. This means that employers cannot refuse to employ PWDs due to their conditions, deny services and adjustments, or exclude PWDs from the workplace. In both countries' regulations are articles that specify job quotas for PWDs. In Indonesia, the employment quota is 2% for government companies and 1% for private companies. However, the difference between Japan and Indonesia regarding employment for PWDs lies in the fact that there are no specific levies and subsidies within Indonesia's regulation, creating a gap between the law and its implementation. This situation is different from Japan, which implements levies and subsidies for companies.

In terms of consideration in judicial proceedings, Japan has clearer regulations and procedures to ensure the rights of persons with developmental disorders. In judicial proceedings in Japan, there are specific policies and regulations in place. Indonesia, however, have no specific policies or regulations that accommodate or provide considerations for individuals with developmental disorders in judicial proceedings. Consequently, individuals with intellectual disabilities involved in legal matters in Indonesia are still susceptible to mistreatment due to the lack of specific protection.

Indonesia, unlike Japan, has no specific institution that focuses on supporting individuals with developmental disorders. All support centres in the country focus on assisting individuals with various types of disabilities. However, families can request home visits for Applied Behaviour Analysis therapy, utilising everyday environments, and online consultations through appointments with several non-government institutions, such as Autism Recovery Network and Uniqkids Autisma. Families are also encouraged to join various supports groups, especially those tailored to children with developmental



disorders. Most support groups primarily concentrate on autism, with one notable example being Teman Autis, a forum that provides information and support for autism.

Indonesia is actively working towards creating a more inclusive society, especially for individuals with developmental disorders. The Directorate of Family Health (2020), under MOH, has established curriculum and training institutions for healthcare workers to conduct stimulation, detection, and early intervention for children development. These training institutions are accredited by the Badan Pelayanan Kesehatan (Health Service Agency) and Badan Pendidikan dan Pelatihan Keuangan (Financial Education and Training Agency). Both Japan and Indonesia mandate designated ministries and government agencies to ensure a sufficient workforce for developmental disorders. Furthermore, numerous researchers and institutions in both countries are actively conducting research on developmental disorders at various scales.

### 5.3. The Philippines

Japan and the Philippines both recognise the importance of early detection and intervention for developmental disorders. The Government of the Philippine (2013a), through Republic Act No. 10410, acknowledges the critical significance of the age 0–8 years old period in educational development. This legislation signifies the government's commitment to strengthening the early childhood care and development system by allocating funds for these initiatives. This regulation outlines specific objectives for children with developmental disorders, including the establishment of an efficient system for early identification, prevention, referral, and intervention for a diverse range of children with special needs from 0 to 4 years old.

While Japan ensures the accessibility of early detection through mandatory checkups, the Philippines, through the Philippine Health Insurance Corporation or PhilHealth (2017), provides benefit packages for children with developmental disorders under 'Z Benefits'. These packages encompass assessments, plans, tests, and therapy sessions. This programme ensures that all the Filipino children can access early detection and intervention for developmental disorders before entering elementary school. Sagun et al. (2020) also asserted that early detection and intervention for children are further strengthened by the establishment of the Early Detection and Intervention Council, as mandated by Executive Order No. 778/2009.

In terms of family and developmental support, the Philippines lacks a mechanism like Japan's Child Consultation Centre. Consequently, the Philippines relies on NGOs to assist families during children's early developmental stages. One notable organisation is the ASP, a national non-profit dedicated to the well-being of individuals on the autism spectrum disorder. Support groups and training sessions are available for persons with autism, parents, siblings, as well as professionals and the public. A difference lies in the fact that most organisations in the Philippines primarily focus on autism spectrum, leaving other variations in developmental disabilities under limited care. Furthermore,

unlike Japan, the Philippines lacks specific childcare facilities and services that focus on children with developmental disorders. Parents and guardians can recruit and/or utilise general childcare facilities. They are also encouraged to provide necessary information, reasonable accommodation, and proper care of children with developmental disorders.

Both Japan and the Philippines enable parents and schools to meet and consult with each other to formulate individual instruction plans and individual educational support plans to help children with disabilities, including developmental disorders, receive education tailored to their specific needs. The Philippines' Department of Education (2009) regulated Department Order No.72/2009 to increase the participation rate of children with special needs in education, resulting in a similar categorization of education for children with special needs between the Philippines and Japan. Roxas, Agustin, and Vallejo (2019) elaborated that education for children with special needs in the Philippines is categorised into Special Class, Itinerant Teaching, Resource Room, Pull-out, as well as Integration and Inclusion. The differences between Japan and the Philippines in the forms of education for students with special needs, including developmental disorders, lie in the existence of "pullout" in the Philippines' regulations. It refers to a programme where students with special needs are temporarily taken out of their regular classroom setting to receive specialised instruction or support services focusing on their individual needs such as speech therapy, behavioural intervention, etc. This is a method not regulated or known in Japanese law, where education for children with developmental disorders is categorised in special schools, special classes, and resource rooms. Furthermore, another difference between Japan and the Philippines lies in the implementation in the latter country. There is still a lack of reports about the implementation of inclusive education in the Philippines (Muega, 2016). In addition, a report from Manuel and Gregorio (2011) stated that the Philippines faces multiple challenges, including weak enforcement, a lack of political will, insufficient funding, and delivery capabilities to fully implement inclusive education on a national scale. While the report is quite dated, it is noteworthy to emphasise that no recent academic publications specifically address this subject within the framework.

While after-school support in Japan emphasises day services during long holidays, in the Philippines, after-school support is mostly initiated by NGOs and focuses on the integration and capability improvement of children with developmental disorders. The Philippines has the Center for Autism and Related Disorders (CARD), which has developed its own intervention model called the Functional Integrated Team Approaches to enhance the potential of individuals with autism in all aspects of their lives. CARD classifies children into three main categories that available upon request for outside-of-school activities, namely:

- Pre-school (2–6 years old), which aims to improve children's basic living skills, development, speech and language abilities, as well as motor skills, socio-emotional development, and self-help skills.

- Primary (7–14 years old), which focuses on extending children’s capability in basic living skills and overall development. Children are grouped based on age, intellectual capability, communication skills, and behaviour.
- Transition (15–17 years old), which aims to prepare children for adulthood through materials such as work behaviour and adaptation, communication skills, functional academics, physical education, domestic skills, and self-care skills.

The Philippines and Japan have similar regulations for information sharing amongst government institutions, schools, hospitals, and other supporting organisations, if there is legal consent from the owner. Specifically, Marella et al. (2016) stated that support organisations for developmental disorders in the Philippines can request detailed information about persons with developmental disorders as a fundamental step in establishing new programmes. This enables support organisations to implement better programmes for assisting people with developmental disorders, as they have proper data to be measured and analysed.

Both Japan and the Philippines also have similar policies regarding employment support, where both countries have institutions designated to provide counselling, vocational training, as well as job placement. Table 5.3 specifically shows the differences between the two countries.

**Table 5.3: Employment Support in Japan and the Philippines**

Item	Japan	The Philippines
Institutions	Hello Work Local Vocational Centres for Persons with Disabilities Employment and Livelihood Support Centres for Persons with Disabilities	Rehabilitation Sheltered Workshop National Vocational Rehabilitation Centre Centre for the Handicapped
Accessibility	Available in most cities or prefectures	Availability limited to Quezon City (Rehabilitation Sheltered Workshops), Dagupan City, Cebu City, and Zamboanga City (National Vocational Rehabilitation Centre) and Cotabato City (Centre for the Handicapped)
Scopes of Training	Depends on individual skills and characteristics	Scientific massage, handicraft, tailoring/dressmaking, watch repair, computer repair, canteen management

Source: MHLW (2023), Philippine Information Agency (2023).

Based on Table 5.3, it can be concluded that the main difference between Japan and the Philippines lies in the accessibility of employment support organisations. In the Philippines, not all cities and provinces have job support institutions for persons with disabilities. Furthermore, institutions in the Philippines also have a limited scope of training primarily focusing on physical labour, whereas Japan tends to provide training based on individual skills and characteristics.

Community support regulations in the Philippines have similar provisions to Japan in terms of benefits for PWDs. Individuals with developmental disorders are eligible by law, as stated in RA 7277, amended by RA 9442 by the National Council on Disability Affairs (2007b). PWDs, including those with developmental disorders, are entitled to receive multiple benefits, such as discounts in public facilities, hospitality services, medicines, admission fees for leisure activities, financial and resources aid, insurance, social security, affordable housing, and basic commodities. The amount of the discount varies between each category. However, the Philippines does not have specific policies regarding support for persons with developmental disabilities in their daily activities, as well as adult guardianship.

Advocacy for persons with developmental disorders in Japan and the Philippines shares similarities in ensuring equal opportunities and employment for PWDs. The National Council on Disability Affairs (2012) enacted RA 10524 to secure the rights of equal opportunity for PWDs, regulating anti-discrimination laws and mandating a 1% employment quota for companies to hire individuals with disabilities. According to Rule VI, private entities that employ PWDs, whether as regular employees, apprentices, or learners, are entitled to an additional deduction – equivalent to 25% of the total amount paid as salaries and wages to PWDs – from their gross income.

Both Japan and the Philippines have similar policies to protect students from bullying. The Government of the Philippine(2013b) ratified RA 10627 to safeguard all children, including those with developmental disorders. This regulation requires schools to address the existence of bullying in their respective institutions. Schools must establish procedures and strategies for reporting acts of bullying, conducting investigations, restoring safety, protecting victims and witnesses, and providing counselling or referrals to appropriate services. However, the regulation does not include a specific clause addressing bullying of children with developmental disorders.

The Philippines currently lacks specific regulations to protect the rights of persons with developmental disorders in judicial proceedings. According to the Commission on Human Rights of the Philippines (2017), the legal system still falls short in providing adequate safeguards for the fair trial rights of PWDs. One of the primary issues identified is that physical or mental impairments significantly impact the 'probative value' of the person's testimony. This is exacerbated by the failure of courts to provide sensitised court personnel and well-trained interpreters to assist the litigants throughout the legal process. Additionally, judges often lack training in handling cases involving PWDs.

In contrast, Japan has implemented measures to ensure that persons with developmental disorders can receive reasonable accommodations such as interpreters, communication aids, and adjustments to the courtroom environment to meet their specific needs. In some cases, a welfare commissioner is appointed.

Notably, the Philippines has taken a step towards addressing this issue through the ratification of a Memorandum Circular about Treatment for Person with Deprived Liberty (PDL) with Special Needs by the Bureau of Jail Management and Penology in 2020. This memorandum aims to eliminate discrimination against PDLs and visitors, enhance the quality of life of PDLs with disabilities in jail, and promote economic independence, rehabilitation, and self-development. To prepare PDLs with disabilities for life after prison, they are provided with opportunities for vocational skill training and employment support under the Technical Educational and Skills Development Authority.

Like Japan, where released PDLs receive assistance through consultations and support to reintegrate into the general community, the Philippines is making efforts to ensure that individuals with developmental disorders have a supportive transition back into society.

In terms of family support, the Philippines and Japan have differences due to the Philippines' regulation and context. In the Philippines, families of individuals with developmental disorders can request for counselling from the city or municipal social welfare and development Office (CSWDO) in both individual and family sessions. The CSWDO can assist children with developmental disorders whose biological parents are not able to take care of them through alternative family support services. Its authority, especially in cases where the CSWDO can provide family support services, is necessary where biological parents neglect the care of children including those with developmental disability. In Japan, family support mostly focuses on additional support from experts and mutual support between family members through the Peer Support Promotion Project. This project aims to create a welcoming space where individuals facing similar challenges or parents of children with developmental disorders can gather. It also offers temporary childcare services to facilitate participation in these gatherings. Additionally, home-visit nursing care (support for nursing care and housework by supporters other than family members), short-term admission, and temporary daytime support upon request are also available. These supports have limited availability on the Philippines. However, NGOs such as ASP, Happy Homes Housing Cooperative and Association of Adults with Autism Philippines provides consultation support using ICT.

The Philippines faces challenges in establishing support centres for developmental accessibility in each city or province, unlike Japan. As a result, individuals often rely on hospitals and governmental institutions that focus on disabilities in general to gather information. Valenzuela et al. (2022) noted that some people opt for established local communities to share information and serve as a support centre for developmental disorders. These communities primarily focus on providing information about managing developmental disorders and gaining necessary access.

Both the Philippines and Japan are actively working to improve conditions for PWDs, including those with developmental disorders. To address human resource needs, the NCDA (2007) in the Philippines enacted RA 9433, mandating human resources development for public social workers. This includes recruitment, talent development, and proper benefits. Research in the Philippines on developmental disorders often centres around education, assistive devices, the parental role in developmental disorders, the transition and adulthood of individuals with developmental disorders, and health assessments. These areas will contribute to a comprehensive understanding of the challenges and support mechanisms for individuals with developmental disorders in the Philippines.

#### 4.5. Viet Nam

The Government of Viet Nam mandates screening to detect the presence of developmental disorders in children; identification and intervention services, especially for ASD, are available in the country although the situation is different in Japan in terms of implementation. Research by Tran et al. (2015) indicated that Viet Nam faces challenges in the detection and intervention of developmental disorders, including:

- Lack of well-trained professionals
- Limited tools for evaluation and diagnosis
- Outdated and unstandardised practices, raising questions about the quality of services
- Absence of scientific evidence base for services
- Lack of official governmental policy to support children with ASD.

These problems pose challenges for Viet Nam, particularly in ensuring equal accessibility for early detection and intervention in developmental disorders, especially for those living in rural areas with limited economic capacity.

However, there have been many positive developments in recent years. The Center for Creatives Initiatives in Health and Population (CCIHP), Medical Committee Netherlands Vietnam, and other major counterpart organisations such as MOH, through the project called I-Thrive, have collaborated to strengthen guidelines on early identification and intervention, and multidisciplinary working mechanism.

As an outcome, the project has not only established Interdisciplinary rehabilitation teams at provincial health facilities but has also ensured that provincial level hospitals in two targeted provinces (Thua Thien Hue and Quang Nam) can now provide sustainable, standard quality interdisciplinary services of physical therapy, speech and language therapy, and occupational therapy. Additionally, the trained staff successfully screened

61,961 children under 5 years old for Intellectual and Developmental Disabilities, with 977 children referred for further assessment and intervention at health facilities.

The project even resulted in agreement and partnership between the CCIHP, Medical Committee Netherlands Vietnam, and DOH to further cooperate in developing interdisciplinary rehabilitation services and the development of national guidelines for children with intellectual disabilities and developmental disorders, especially children with ASD. In line with this, MOH is facilitating the creation and issuance of two technical guidelines (Ha, 2022).

In some cities, parents or guardians can engage in detection and intervention with the help of NGOs.

Training for parents and individuals is also available upon request after screening in Viet Nam. The main difference between implementation in Japan and Viet Nam lies in the availability of the resource centres. Japan has child consultation centres that serve as central hubs offering support to children with developmental disorders and their families, while Viet Nam mostly relies on NGOs such as the Vietnamese International Clinic for Autism

, the Vietnamese Family Autism Advisory Board, VAN, the CCIHP, and the Hanoi Association for People with Disabilities. According to Le (2023), training for parents and individuals with developmental disorders is conducted through several programmes listed below:

- The Portage Program is designed for children with intellectual disabilities, cerebral palsy, and those without formal diagnosis, assessed through the Vineland Adaptive Behaviour Scales (Vineland-3) (reported in studies of implementation and efficacy of the program held in two different regions, Hanoi and Hue)
- Caregiver Skills Training is designed for children with autism and their caregivers (developed by WHO and Autism Speaks; and adapted and implemented in Viet Nam by CCIHP with financial support from the United States Agency for International Development [USAID] since 2019).
- The Online Parents Mediated Intervention Program is designed for parents to understand and collaborate in interventions through an online-based programme. It is situated in resource-constrained settings in suburban and rural areas of Viet Nam and could be considered part of community-based rehabilitation (developed and implemented by the CCIHP and Mosaic).
- The Family Management Intervention Program is designed to ensure the improvement of the quality of life and reduction of the burden of care for caregivers.

In both Viet Nam and Japan, parents or guardians, along with children with developmental disorders, can choose their schools and learning methods. They can also consult with the

school to create an individualised instruction plan. However, there are notable differences in the approach to developing standards for the competency of SPED teachers in these two countries.

Viet Nam has established standards for the competency of SPED teachers through the efforts of Hanoi National University for Education (HNUE). According to Hai et al. (2020), the HNUE is the sole university in Viet Nam with a faculty dedicated to special education at all levels. As a result, it is responsible for designing competency standards exclusively for SPED teachers.

In contrast, Japan's approach involves collaborative efforts between the government, universities, NGOs, and the National Diet Members Caucus for Support on Developmental Disorders to design competency standards for teachers and other educators specialising in developmental disorders.

Furthermore, in Japan, students with developmental disorders aiming to participate in entrance exams for high schools and universities can request reasonable accommodations such as taking the exam in separate rooms and enlarging printouts. In Viet Nam, these specific terms are included in standard regulations, providing a framework for the development of implementation guidelines. This allows schools and educators in Viet Nam to implement accessibility and adjustments tailored to the needs of children with developmental disorders.

PWDs in Japan and Viet Nam can access employment support in the form of vocational training before entering the workforce. According to USAID (2015), vocational training in Viet Nam is specifically designed, encompassing vocational schools that focus on specific skills, school-to-work models, as well as guidance and placement support to help individuals find a job. However, the main differences between Japan and Viet Nam lie in the availability of the resource centres and the programmes themselves. In Japan, various resource centres are spread across the country, including national and prefectural institutions, as well as NGOs. The same cannot be said in Viet Nam, as there are limited centres specifically established to support employment for individuals with developmental disorders. In the case of Viet Nam, job support is mostly provided by NGOs offering vocational training, with some organisations collaborating with local businesses to employ individuals with developmental disorders.

In terms of community life support, Viet Nam has limited resources and services for persons with developmental disorders to conduct daily activities, engage in leisure activities, participate in community interactions, and access suitable housing facilities. This situation contrasts with Japan, where there is a group home program specifically designed to foster a family-like atmosphere, ensuring interaction with residents for people with developmental disorders. The number of users in Japan has consistently increased over the years. However, both countries offer an ICT-based consultation programme upon request. In addition, Japan provides multiple benefits for individuals with developmental disorders, including pensions and discounts for various occasions



and services. In Viet Nam, stipends are provided, in part, to assist with transportation fees for attending school through the USAID programme.

Viet Nam's primary legal framework aimed at promoting the well-being of persons with developmental disabilities, as established by the National Assembly of Viet Nam in 2010, is Law No. 51/2010/QH12 on Persons with Disabilities (*Luật người khuyết tật*). This law ensures a legal foundation for protecting the rights and interests of persons with disabilities in Viet Nam. The National Assembly of Viet Nam (2019) has outlined the Labour Code (*Bộ luật Lao Động*), stating that companies can be legally challenged for employment discrimination against PWDs. However, Viet Nam has not yet implemented specific measures defining what constitutes discriminatory acts in terms of employment, which differs from Japan. In Japan, companies are obliged by law to meet specific quotas for employing PWDs. Companies face levies for non-compliance and receive subsidies for successfully employing a significant number of PWDs.

Furthermore, the difference between Japan and Viet Nam in advocating for individuals with developmental disorders also lies in the availability of specific prevention measures, assessment, and actions needed to address bullying cases. Viet Nam does not have any laws that obligate the prevention of bullying in general and specifically for individuals with developmental disorders. In contrast, Japan requires schools to implement individualised educational support, guidance plans, and measures to prevent bullying.

Both Viet Nam and Japan regulate legal proceedings for PWDs, including developmental disorders. The National Assembly of Viet Nam (2015) enacted the Criminal Procedure Codes (*Nội dung toàn văn*) or Law No. 101/2015/QH13, which stipulates that individuals facing charges and unable to defend themselves due to physical defects, mental disabilities, or those under 18 years old shall have defence counsels appointed by procedural authorities. However, according to Nguyen and Le (2021), there is inconsistency in the terms related to disability within the regulation. The terms 'mental impairment', 'mental disability', 'intellectual disability', 'physical weakness', and 'mental weakness' have not been clearly defined, resulting in inconsistent interpretation and application of the law. This inconsistency means that PWDs in any of these cases may be disadvantaged, as they may struggle to access justice when there is an inconsistent understanding of the law amongst those applying and enforcing it. In Japan, individuals with disabilities, including developmental disorders, can receive reasonable accommodations and other considerations during judicial proceedings. These reasonable accommodations include interpreters, communication aids, adjustments to the courtroom environment, and the provision of welfare commissioners.

While Japan has support centres for developmental disorders in each prefecture operated by local governments, support centres specifically established to support persons with developmental disability in Viet Nam are mainly operated by NGOs. Viet Nam does not have specific institutions established by the government for developmental disabilities, with one exception being the Viet Nam Federation of Disability (VFD). The VFD is an

umbrella organisation working at the national level under MOLISA. It was legalised in 2010 to ensure communications between different groups or organisations such as disabled people's organisations and local NGOs working on disability-related issues from the grassroots level.

Both Japan and Viet Nam have programmes to ensure the availability of human resources specialised in developmental disorders. Both countries conduct human resources training under the national designated ministry, with Viet Nam's assigned ministry being MOH, MOLISA, and MOET. Furthermore, both countries are also conducting various research on developmental disorders and their implementation in their respective countries. In Viet Nam, topics related to developmental disorders is an emerging interest and mostly focus on prevalence, risks factors, intervention and diagnosis, education, family support, as well as employment and well-being.

## Chapter 6

### Conclusions and Recommendations

The research project on 'Current Status and Issues of Healthcare Policies for Persons with Developmental Disorders in Southeast Asia (Healthcare Policies)' was conducted to address the challenges faced by individuals with developmental disorders and their families. This study focused on various aspects of developmental disorders, including ASD, ADHD, and learning disabilities. The research also conducted a situation analysis of developmental disorders in the ASEAN region and identified a number of emerging issues, highlighting the perspectives of persons with developmental disorders and their families.

Additionally, the research has assessed the progress of disability-inclusive development in the ASEAN region and analysed the participation of persons with developmental disabilities in society, including the challenges they face. The aim is to identify areas for improvement to ensure their full and effective societal participation in the long term. Despite progress in some parts of the region, persons with developmental disorders tend to be excluded due to barriers to their participation in mainstream society. The study has identified numerous barriers, including limited access to health services and education in rural areas, difficulties entering the job market, and the need for social protection and extensive support, especially for those entering adulthood.

This research project was developed in partnership with Japan and the AMS to enhance and increase research expertise through international collaboration. The objective is primarily to promote the sharing of good practices and knowledge about developmental disorders such as ASD, ADHD, learning disabilities, aligning with UN resolutions (UN, 67/82, 2012) that emphasise the socioeconomic needs of individuals, families, and societies affected by developmental disorders and associated disabilities.

Based on a comparative study of policies related to developmental disorders in ASEAN countries and Japan, some key conclusions are drawn from the study. These include:

Similarities in the context of policies and situation between ASEAN and Japan:

- In terms of disability policy and public awareness, physical and intellectual disabilities are more advanced in Japan and ASEAN countries. On the contrary, psychosocial disabilities and developmental disorders (e.g. ASD, ADHD, learning disabilities/disorders) could receive more focus in the future.
- Approximately 10% of the total population in Japan and ASEAN may have developmental disorders. There is an urgent need to strengthen the quality and quantity of human resources contributing to the support of individuals with developmental disorders. This includes enhancing systems that provide professional support, regardless of age, while considering the understanding of

the local population.

Differences in the context of challenges related to developmental disorders between ASEAN and Japan:

- In Japan, the ageing society arrived earlier than in ASEAN countries (Japan in 1994, Viet Nam in 2034, Indonesia in 2051, and the Philippines in 2068). Japan has also been a pioneer in addressing the ageing of individuals with developmental disorders, such as through the establishment of group homes.

An individual can have several types of developmental disorders, necessitating a comprehensive perspective and response. In other countries, activities are often carried out for each specific type of developmental disorder, leading to the dispersion of funds and other resources (Indonesia established IDD Net as a response, drawing inspiration from Japan's case, see Chapter 4, Box 7). There is a need for co-creation and synergy in human resources development and the allocation of the right people to the right places, considering the situations of individuals with developmental disorders and their families in each country.

Based on the conclusions, several frameworks for actions are recommended:

- To further facilitate exchanges amongst persons with developmental disorders and their parents, lawmakers, government officials, academic researchers, and other relevant stakeholders in ASEAN and Japan, capacity-building initiatives should be implemented. These initiatives aim to enhance inclusivity and understanding of persons with developmental disorders themselves.
- Awareness of ASD is increasing, but there is a growing gap in addressing ADHD and learning disabilities. A more specific approach is needed to bridge this gap and learn lessons between ASEAN and Japan. This collaboration could serve as an online think tank for collecting data and information, and enhancing policies and practices related to developmental disorders in the ASEAN region and Japan.
- The creation of a developmental disorder-friendly society for all needs to be elaborated in the target countries. This requires stronger collaboration between ASEAN countries and Japan in the field of developmental disorders and exploring new initiatives, such as community life care through group homes and facilitating work transition from vocational training centres for persons with developmental disorders to locally available workplaces in partnership with the private sector.
- Disparities in the lifespan of individuals with developmental disorders and the challenges of an ageing society highlight the importance of lifelong learning and comprehensive support. This involves implementing effective education and training for public servants like police officers and schoolteachers in the AMS. Policy shifts should focus on identifying lifelong needs, expanding education access,

enhancing employability, and supporting parents and caregivers in caring for their children with developmental disorders.

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