

## INCLUSIVE HEALTHCARE FOR DISABILITY ACROSS LIFESPAN – EPIDEMIOLOGY AND SERVICES

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### ABSTRACT

**Disability is common and affects 12 percent of Singaporean children and youths. In accordance with Singapore's commitment to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Sustainable Development Goal (SDG) 2030, our nation has made notable social advancement towards disability inclusion in the recent decades. However, healthcare inequity for persons with disabilities (PWD) remains a challenge in Singapore. This article presents a summary of the global and local epidemiology of disability, with a special focus on special needs children and youth with disabilities. An overview of the social, educational, and community services to support children and youth with disabilities, and their families, is also presented, aiming to aid the family physician's pivotal role in providing equitable and holistic primary care for these vulnerable individuals. Lastly, this article examines the factors affecting healthcare equity for the PWD and discusses principles and strategies to improve health equity and outcomes for children and adolescents with disabilities in Singapore.**

**Key Words: Child, Adolescent, Disability Inclusion, Sustainable Development, Health Equity**

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### INTRODUCTION

#### Epidemiology of Disability – Global Prevalence and Disease Burden of Disability

The World Health Organisation (WHO) estimates that 16 percent of the world population, or 1.3 billion people, have moderate to severe disabilities<sup>1</sup>. Contrary to common misconceptions that disability is conundrum only plaguing the low- and middle-income countries, it is more prevalent in high income countries than in low-income countries (21.2 percent versus 12.8 percent). In high-income countries with better perinatal care, more babies survive with congenital disabilities and disabilities acquired postnatally, e.g., Retinopathy of Prematurity and Cerebral Palsy. In addition, strong childhood surveillance and early diagnosis for developmental disabilities such as Autism has resulted in higher incidence and rising prevalence of developmental

disabilities in recent decades. Better healthcare also resulted in better survival from conflict, trauma, and non-communicable diseases, with more living longer albeit with acquired disabilities. The rising incidence of mental health conditions in developed countries also accounts for the rising prevalence of psychosocial disabilities globally. Lastly, with a 40 percent increase in people aged >60 years in the last decade,<sup>2</sup> ageing-related disabilities such as dementia are also rising. Gender-wise, disability is more common among females than males (18 percent versus 14.2 percent), which can possibly be attributed to decreased access to healthcare and social support due to gender inequality in some countries or an overall longer life expectancy in females than males.<sup>1</sup>

To understand the drastic change in epidemiology of disability over the past two decades, it is important to appreciate the major shift in the WHO's definition of disability in 2001. Prior to 2001, disability was defined based on the medical deficit model, and classification was according to the diseased state of the body. In 2001, WHO re-defined disability by adopting a functional approach based on the bio-psycho-social model,<sup>3</sup> and thenceforth classified disability based on the International Classification of Functioning, Disability, and Health (ICF). Since 2001, the global definition of disability is "any condition of the **body or mind (impairment)** that makes it more difficult for the person with the condition to do certain activities (**activity limitation**) and interact with the world around them (**participation restrictions**)". Disability is thus the result of the interaction between health conditions and a range of environmental and personal factors. Hence since 2001, disability now encompasses physical (congenital or acquired), sensory (deafness or blindness), developmental, cognitive (or intellectual), and psychosocial (or mental) disabilities.

#### EPIDEMIOLOGY OF DISABILITY IN SINGAPORE

In Singapore, there has been no single and consistent source of disability statistics. Services for PWD are administered by different ministries across lifespan. Hence, the prevalence and disease burden of disability has been estimated at different times by different ministries, often using different definitions, terminologies, and measurement methods. Thus far, ministries involved in disability measurement include the Ministry of Social and Family Development (MSF), Ministry of Health (MOH), Ministry of Education (MOE), and Department of Statistics of Ministry of Trade and Industry (DOS, MTI). There was also information from large-scale studies conducted by researchers in the universities and national social bodies, e.g., the National Council of Social Service, that attempted to shed light on this matter.

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In terms of definition, the MSF defined PWD in the 3rd Enabling Masterplan (EMP3) and the latest Enabling Masterplan 2030 (EMP2030) as “those whose prospects of securing, retaining places and advancing in education and training institutions, employment and recreation as equal members of the community are substantially reduced as a result of **physical, sensory, and intellectual disabilities** as well as **autism**”. In the social service sector, these are often termed as “visible” disabilities. This definition is in contrast with the WHO’s broader definition, which also includes “invisible” disabilities.

Invisible disabilities are **psychosocial disabilities and other developmental disabilities** that often lead to significant challenges in functioning in daily living contexts, such as work, school, or communities. Examples of psychosocial and developmental disabilities are Schizophrenia, Mood disorders, Dementia, Attention Deficit Hyperactivity Disorder (ADHD), Asperger’s Syndrome, Dyslexia, Dyspraxia or Developmental Coordination Disorder, Social Communication Disorder, and Dyscalculia.

To estimate the population prevalence and disease burden of all disabilities in Singapore across all ages based on the globally referenced WHO’s definition, the prevalence estimates from MOH, MOE, MSF, and population denominators from Department of Statistics (DOS) of MTI<sup>4</sup> are used, as below:

**1. Visible disabilities (congenital, physical, sensory, intellectual, moderate to severe Autism)**

- a. For children from birth to four years old, MOH reported a birth defect rate of 30 per 1,000 live births (**3 percent**).<sup>5</sup> Hence it is estimated that around **5,000 children from birth to four years old** are affected by congenital disabilities.
- b. For children and youths from 5-19 years old, MOE reported the prevalence of sensory impairment, physical impairment, autism spectrum disorder, and intellectual disability to be **2.1 percent** among school age children. Hence there may be **13,000 children and youth aged 5-19 years old** affected by visible disabilities such as physical, sensory, and intellectual disabilities, and Autism.
- c. For adults aged 20-49 years old, MSF reported via the 3rd Enabling Masterplan that self-reported disability was prevalent among **3.4 percent** of adults aged 18-49 years old. Hence there may be **59,000 adults aged 20-49 years old** affected by visible disabilities.
- d. For adults aged 50 years old and above, MSF reported via the 3rd Enabling Masterplan that self-reported disability was prevalent among **13.3 percent** of those aged 50 years and above. Hence there may be **200,000 adults aged 50 years and above** affected by visible disabilities.

- e. Based on the above, there are in total about **277,000 people in Singapore across all ages** who have visible disabilities (congenital, physical, sensory, intellectual, moderate to severe Autism).
- f. The latest National Population Census 2020 conducted by the Department of Statistics of MTI reported the number of people in Singapore with limitations in daily basic activities using the Washington Group’s questionnaire’s standard and wider threshold definition. The standard threshold includes people with severe difficulties (unable to perform or had a lot of difficulty) in at least one basic activity, including seeing, hearing, remembering, self-care, communicating, or moving around. With this standard, there were 3 percent of people in Singapore aged above five years old who experience plenty of challenges in daily activities. On the other hand, the wider threshold includes all who had some difficulty in performing at least one basic activity. With this standard, there were 348,546 people or 11 percent of the Singapore population aged five years and above who had some difficulty in at least one basic activity in living. As there was no concurrent information regarding the impairment in body and structures of these study individuals, these are not taken as official prevalence of disability in Singapore. Another study used the standard threshold of the Washington Group questionnaire, and similarly reported a prevalence of 3.1 percent (95 percent CI: 2.4-4.1). When separated by types of activity limitation, mobility (58 percent) was the most prevalent, followed by vision (26 percent), cognition (16 percent), hearing (9.7 percent), and self-care (6.5 percent).<sup>6</sup>

**2. Invisible disabilities (psychosocial/mental, developmental disabilities)**

- a. **Mental health conditions** have been of increasing concern in recent years, exacerbated by the pandemic. Last year, suicide rates reached a record high in the last two decades, especially among the young and elderly. Based on MOH’s National Population Health Survey, mental health conditions are prevalent in **13.4 percent** of those aged **18-74 years old** in Singapore. This indicates that psychosocial disability could be affecting **405,500 people aged 18-74 years old**.
- b. Among the youths, the NUS Youth Epidemiology and Resilience (YEAR) Study studied 3,336 young people aged 10-18 years old between 2020 to 2022. The first phase of the study was based on a youth self-reported survey, whilst the second phase involved diagnostic evaluation of respondents who self-reported clinical-level mental health symptoms. Results from the self-reported survey showed that 33 percent of the youth had internalising mental

health symptoms such as depression, anxiety, and loneliness, with those aged 14-16 more severely affected. In addition, 17 percent had externalising mental health symptoms, such as hyperactivity, rule-breaking, and aggression. In the second phase with clinical evaluation, **12 percent** of the adolescents met full diagnostic criteria for having at least one current mental health disorder. Another 6 percent of adolescents had previously met criteria for at least one disorder more than a year ago and are no longer meeting the criteria for the same disorder. Taking a conservative prevalence of 12 percent, the number of adolescents aged **10-19 years old** with psychosocial disabilities is estimated to be about **50,600**.

- c. Children and adolescents with **developmental disabilities** often suffer academically and emotionally under the rigorous educational system in mainstream Singapore schools, with many acquiring secondary mental health comorbidity as they transit through the schooling system. Local statistics on the prevalence of these developmental disabilities are lacking. Based on information from the MOH's Child Development Programme, developmental delay is found in 15 percent of the pre-school population,<sup>7</sup> though some will improve with early intervention. Developmental disabilities often do not exist alone but co-exist with other developmental disabilities.<sup>8</sup> Affected individuals also experience higher prevalence of secondary mental health co-morbidities<sup>9,10</sup> and health issues,<sup>11,12</sup> e.g., obesity and gastro-urinary issues. Internationally, prevalence rates for various developmental disabilities in the school age population ranges from 3.5-20 percent, as below:
- i. **Autism** is estimated to be **1 in 150** in Singapore.<sup>13</sup> Worldwide, prevalence estimates have risen steadily over past decades to 1.5 percent.<sup>14</sup> About 37.9 percent of persons with Autism have intellectual disability (IQ score  $\leq 70$ ).<sup>15-17</sup>
  - ii. **ADHD** is estimated to be about **4.6 percent** locally<sup>18</sup> and 5.3 percent globally.<sup>19</sup>
  - iii. **Social communication disorder** in overseas studies is said to affect 7.5 percent of children, though local data is not available.
  - iv. **Dyslexia** is reported by MOE to have prevalence of **3.5-4.5 percent** among children aged 9-13 years old,<sup>20</sup> whilst international prevalence is 3-20 percent.<sup>21</sup>
  - v. **Dyspraxia** (or Developmental Coordination Disorder) is estimated to have a prevalence of **5-6 percent** among children and adolescents<sup>22</sup> but there is no local data.

vi. **Dyscalculia** is less researched and is estimated to affect **5-6 percent** of schoolchildren in United Kingdom.<sup>23</sup>

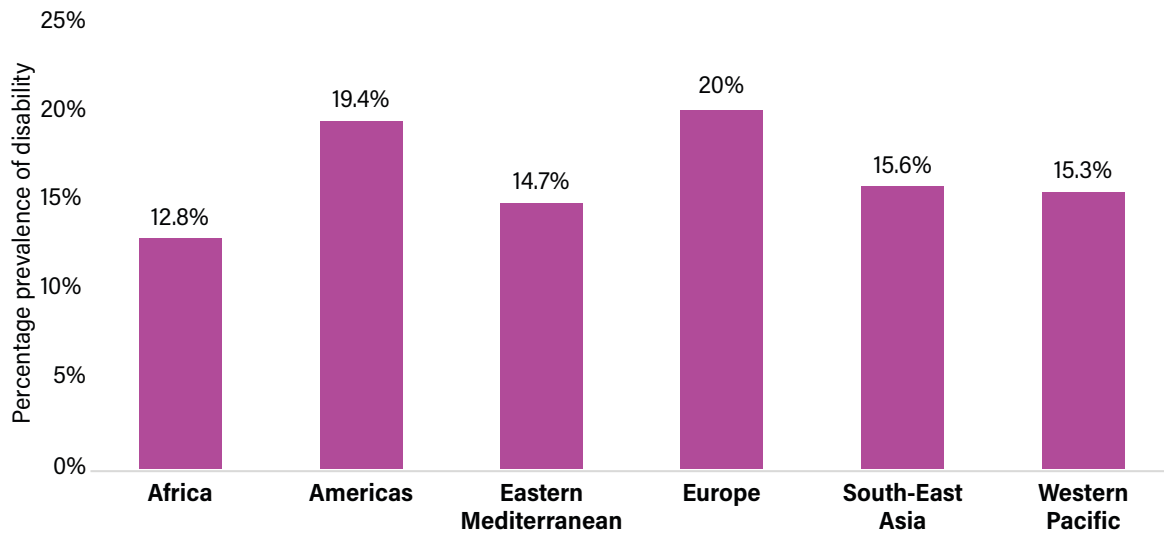
- d. Based on figures released by MOE in 2022, there are about **34,000 (5.5 percent)** children in MOE schools with special educational needs. Of these, **27,000 (4.4 percent)** are mild and supported in mainstream schools. The other **7,000 (1.1 percent)** with moderate to severe needs attend the Special Education (SPED) schools. However, this figure excludes those who are educated in private and international schools after compulsory primary school education. MOE's school-based diagnostic assessments are also difficult to access as a needs-based approach is preferred over diagnostic approach. Based on the 50 percent under-estimation of children with disabilities in special schools compared to NCSS statistics (1.1 percent compared to 2.1 percent), the prevalence rates of children with disabilities in mainstream schools is thus likely an underestimation as well.

### 3. Total disease burden of all disabilities in Singapore

- a. Summing up the above estimates, the **total population of people with visible and invisible disabilities in Singapore** can be up to **760,000 across all ages**. Based on WHO's definition and a 2020 resident population of 4 million in Singapore, the estimated overall prevalence of all disabilities across all ages is **19 percent**. This estimate is akin to those reported in other high income and developed countries in South-East Asia, European, and American WHO regions in **Figure 1**.
- b. For children and adolescents (aged less than 20 years old), the **total children and adolescent population with visible and invisible disabilities** in Singapore is estimated to be around **96,000 or 12 percent**.

In summary, disability is heterogenous and common. Almost 1 in 5 people have one form of disability or another. Becoming disabled at one point in life is almost a certainty for every human being. In an average primary care practice who attends to 30 patients a day, the family physician would typically be attending to at least 1 to 5 PWD per day. If not, it begs the question "why?"

**Figure 1. Prevalence of disability by WHO region, 2021<sup>1</sup>**



Source: *Global Burden of Disease data, 2021*

**INCLUSIVE HEALTHCARE FOR PWD**

PWD have higher health care needs.<sup>24</sup> They are three times more likely to have Diabetes, have 2.4 times higher mortality rate, and are 50 percent more likely to suffer catastrophic health expenditure.<sup>1</sup> Yet, despite their greater needs, PWD are not getting the healthcare they need as often, as much, and as well as the general population. While substantial progress has been made in many countries in recent years, PWD continue to experience a wide range of health inequities.<sup>25</sup> PWD are three times more likely to be denied healthcare and four times more likely to be treated badly by healthcare systems.<sup>1</sup> Globally, PWD face a staggering 10-to-20-year life expectancy gap.<sup>1</sup> This poor outcome is not primarily due to their underlying health condition, but rather the lack of inclusive and equal healthcare as the general population.<sup>24</sup> Such health inequities were made starkly apparent in the recent COVID-19 pandemic. In the United Kingdom, though PWD constitute only 16 percent of people infected, 59 percent of those who died from COVID-19 were PWD.<sup>26</sup> In Singapore, health inequities have similarly been reported before and during the pandemic.<sup>27,28</sup>

PWD have the same, and equal, right to the highest attainable standard of health as any human being. This right is inherent, universal, and inalienable, and is enshrined in international law through human rights treaties such as the Convention on Rights of Persons with disabilities (UNCRPD) and the Sustainable Development Goal 2030 of the United Nations, for which Singapore is a member of. Financial investment in disability-inclusive healthcare has also been shown to have good returns. With every dollar spent on disability inclusive cancer prevention and control, the return is ninefold. Similarly with every dollar spent on disability-inclusive initiatives for prevention and care of noncommunicable diseases, the return is tenfold.<sup>1</sup> These cost-effectiveness data add to the push in making healthcare

inclusive and equitable for PWD. Thus inclusive healthcare is one of the priority areas in the Enabling Masterplan 2030, in line with the vision and mission of the United Nations Sustainable Development Goal 3 to achieve Universal Health Coverage by 2030.

**HEALTHCARE NEEDS OF PWD**

To provide for the health needs of PWD equally and inclusively, the medical personnel ought to first have a strong understanding of the health issues (other than the primary underlying condition) that commonly affect PWD.<sup>29</sup> These are summarised as below:

**More Acute Illnesses**

PWD have a “thinner margin of health” and are more likely to fall sick from the usual common acute illnesses that affect non-disabled people, e.g., the common cold. In addition, due to their underlying primary conditions, they may be more prone to certain acute illnesses, e.g., Urinary Tract Infection and pressure sores for those with spinal injuries, aspiration pneumonia, and seizures in those with dementia.

**More Chronic Diseases**

Due to physical restrictions and limitations from the underlying disabilities or isolation secondary to social factors, PWD have fewer opportunities to participate in wellness initiatives for disease prevention (e.g., vaccination and cancer screening) and to maintain a healthy lifestyle (e.g., exercise campaign). Some primary conditions also predispose the PWD to higher incidence of secondary chronic health conditions, e.g., Dementia in Down Syndrome. As such, PWD have a higher incidence, earlier onset, and greater morbidity and mortality from non-communicable diseases, e.g., chronic heart disease, diabetes, hyperlipidaemia, and cancer.

## More and Longer Rehabilitation

PWD face more secondary functional loss if they fall sick. Their rehabilitation needs are often more complicated, and they take longer to recover in community rehabilitation facilities as well.

## More Mental Health Needs

PWD have a higher incidence of mental health issues, e.g., behaviour of concerns e.g., self-harm or aggression in Dementia, Autism and Intellectual disability, Depression and Anxiety in ADHD, and Obsessive-Compulsive Disorder and Schizophrenia in Autism. Such mental health and behavioural challenges further complicate access to health services and the quality of care delivered.

## Higher Social Needs

PWD usually require more and longer periods of medical supervision to ensure compliance and adherence to prescribed healthcare regimen. Often, increased financial and social assistance are also needed, given the higher likelihood of lower income status due to generally lower employability.

## Limitations of Technology

PWD benefit from usage of assistive devices. These can be costly or, in some cases, not available. When accessing healthcare in medical facilities, PWD also require accessible examination rooms and medical equipment.<sup>30</sup> In addition, PWD are also less able to access health applications and online resources if these webpages and software do not fulfil accessibility standards.<sup>31</sup>

For holistic care of PWD, the family physician will need to be acquainted with the community services and resources that complement the health services provided. The subsequent sections will highlight mainstream community services governed by various ministries, administered by national agencies, and provided by major community partners.

## COMMUNITY SERVICES FOR CHILDREN AND YOUTH WITH DISABILITIES AND CAREGIVERS

The community services for children and youth with disabilities and their caregivers are organised based on their life stages, i.e., preschool and school age, as the primary ministries in charge are different, thus the social or educational services are organised differently. Related health services that interface with these community services are highlighted as well.

### Preschool Services

In the preschool period, all early intervention programmes for preschool children with developmental needs are provided by social service agencies and administered by the Early Childhood Development Agency (ECDA). The ECDA is jointly overseen by MOE and MSF and hosted

under MSF. Healthcare needs are under MOH, chiefly involving the Health Promotion Board (HPB) and the Child Development Programme.

## Healthcare Services

Congenital and perinatally acquired disabilities are often detected prenatally, at birth, or in infancy. These conditions are often managed by respective specialists from detection until they enter adulthood, e.g., by the Geneticist for syndromal and rare disorders; the neurologist for cerebral palsy and epilepsy syndromes; congenital or acquired blindness by paediatric ophthalmologists; and deafness by the ear, nose, and throat specialist. The respective primary specialist will often be the case manager for the healthcare needs of these children, supported by medical social workers and allied health teams in the tertiary setting.

For developmental and behavioural disorders, surveillance begins early in the preschool period through periodic developmental screening using the Child Health booklet.<sup>32</sup> The Child Health booklet has incorporated red flags for autism and screening items for delayed developmental milestones. Parents are encouraged to surface any concerns to the primary care team or private community paediatricians.

Children with developmental concerns are then referred to the Child Development Programs (CDP) in KK Women's and Children's Hospital (KKH) or National University Hospital for further diagnostic evaluation and interim services.<sup>33</sup> Last year, the Department of Child Development in KKH received about 5,000 new referrals for evaluation of developmental and behavioural concerns. Other than the CDP programmes in publicly funded hospitals, specialist evaluation may also be conducted at private clinics by developmental and behavioural paediatricians.

Upon confirmation of developmental needs, the preschooler can then be referred to the SG Enable for placement in a suitable Early Intervention (EI) programme.

## EARLY INTERVENTION SERVICES

The Early intervention programmes under ECDA include centre-based programmes and pre-school-based programmes.

### Centre-Based Early Intervention Programmes

The centre-based programmes, namely the EIPIC@ Centre and EIPIC Under-2s, are for children from birth to six years old who require medium to high levels of Early Intervention (EI) support. Support is provided by EI professionals and Allied Health Professionals (AHPs), guided by an Individualised Educational Plan (IEP) for the child. Caregiver training and support are often provided at the EIPIC centres as well. With long wait times for publicly-funded early intervention programmes as a result of the soaring numbers of referrals to EIPIC in recent years, private intervention centres have been appointed by ECDA to provide subsidised early intervention programs (EIPIC-P).

## Early Intervention in Preschools

In recent years, early intervention programmes in preschools for children with mild to moderate developmental needs have flourished. Through collaborations with early childhood education professional groups and the National Institute of Early Childhood Development (NIEC), preschool educators are increasingly trained on early identification of developmental needs among pre-schoolers and supporting their developmental needs holistically in natural settings.

Currently, children with moderate needs who have improved in centre-based EIPIC programmes may be stepped down to be integrated into preschools under the DS-plus programmes. These children will be supported by EI professionals from the EIPIC centres, who will co-teach with early childhood educators in the preschools. In addition, a pilot programme for inclusive preschool model, the InSP programme, is currently being trialled. The InSP programme caters to children with developmental needs aged three to six who require medium levels of early intervention support, including children with hearing loss requiring signing. This is currently being implemented in six childcare centres and one MOE kindergarten. An older programme, the Integrated Child Care (ICCP) Programme, has been phased out.

For children with mild needs, preschool educators in K1 and K2 may identify and refer children with mild developmental and behavioural needs to the Development Support and Learning Support (DS-LS) team for screening and diagnostic evaluation. These children can then be supported on-site in preschool by Learning Support Educators (LSEds) and Allied Health teams from the DS-LS programme. To date, more than 40 percent of children aged five to six in more than 600 preschools are benefiting from the DSLS programme.

In addition to the DS-plus, InSP, and DS-LS programmes, another 4-year pilot programme, Mission I'mPossible (MIP2), is being rolled out in PCF centres by KK Women's and Children's Hospital (KKH), funded by the Lien Foundation. This programme aims to identify and support preschool children younger than five years old by providing an interdisciplinary school-based child development unit. The team, comprising early intervention professionals, curriculum specialists and therapists, social workers, nutritionists, and nurses, will support the children in preschool settings, and support the parents in terms of self-care, family activities, and service navigation. The programme aims to serve 1,800 children aged two months to four years old per year in 16 preschools. About 250 early childhood educators will also be trained to identify and support children with developmental needs.

## SCHOOL-AGE SERVICES

For school-age children and youth, special education and learning support are largely overseen by the MOE, and school health services by MOH's HPB. The MOH also oversees community mental health services through the Agency for Integrated Care (AIC).

### Education Services

Primary school education is compulsory for all children aged 6-15 years old under the Compulsory Education Act 2000, including children with disabilities. In MOE, special education, learning, and behavioural support are provided by the Special Education Needs Division (SEND), which has the Psychological Services Branch (PSB) that works with mainstream schools to support students with mild needs, as well as the Special Education Branch (SEB) that works with the special schools.

### Support from School Personnel

In mainstream schools, specialised personnel known as Special Educational Needs (SEN) Officers (previously known as Allied Educators or AED) are supported by educational psychologists from MOE-PSB to provide learning and behaviour support through individual or small group intervention, skills training, or in-class support. In addition, Teachers Trained in Special Needs (TSN) provide learning support, plan instructional strategies, and adapt lessons for students with special educational needs, and share strategies with other teachers in school.

For academic learning, the Learning Support Programme for English and Mathematics for Primary 1 and 2 students provides extra help with English Language and Mathematics. The TRANSition Support for InTegration (TRANSIT) takes place during Primary 1 to help students with social and behavioural needs develop independence through learning foundational self-management skills. Schools proactively identify these students for support based on information gathered from parents and teachers, and through systematic observations conducted by trained school personnel. TRANSIT will be introduced progressively to all primary schools by 2026.

### School-Based Peer Support

The Circle of Friends (CoF) is a school-based structured peer support intervention for students with social, emotional, and behavioural difficulties. It is a group-based support by volunteer peers with no disabilities facilitated by the Form Teacher. The SEN officers and MOE psychologists will support the Form Teacher. A second programme, Facing Your Fears (FYF), is a mutual peer support programme for secondary school students with special education needs, e.g., Autism, who have emerging anxiety. It is based on Cognitive Behaviour Therapy and involves components like psychoeducation, development of coping skills, emotion regulation strategies, problem-solving, cognitive self-control, and graded exposure. Sessions are conducted in small groups, facilitated by the SEN officers and supported by MOE psychologists.

## Access and Accommodations

Access arrangements in national examinations and accommodations in daily instruction can be made for children with developmental disabilities. Such provisions include extra time, prompters, enlarged fonts through A3 paper, separate rooms for testing, supervised rest breaks, scribing, and use of education-related Assistive Technology. Access to assistive devices in Primary school is fully funded by MOE, whilst youths in secondary school and institutes of higher learning will receive financial support through MOE SEN fund or the Assistive Technology Fund administered by SG Enable. Examples of approved Assistive Technology (AT) devices and support services include:

1. For hearing loss: Digital/FM listening device and related accessories, Text-to-speech software, Speech-to-text software for Hearing Loss, and Communication Access Services (CAS) (i.e., sign language interpretation or note-taking services)
2. For visual impairment: Braille notetaker/display, Braille printing services, Scanning/identification hardware/software, Voice recorders, Headsets (open and closed-back), Multimedia players, Screen readers, Magnification hardware/software, Alternative computer devices (e.g., large screen monitor), Text-to-speech, and Speech-to-text software
3. For Physical disabilities: Alternative keyboards, Alternative pointing devices, Alternative computer devices, Mounting systems, Voice amplifiers, Word prediction software, Speech-to-text software, Writing aids, Augmentative and Alternative Communication (AAC) devices
4. For learning and behavioural difficulties: Reader pens, Phonetic spelling software, Talking calculators, Assistive listening systems, and Text-to-speech software

## Specialised Support and Therapy

The school-based Dyslexia Remediation programme provides support for students with Dyslexia in Primary 3 and 4. Students with Dyslexia in other levels will have access to the MOE-subsidised Main Literacy Programme conducted by the Dyslexia Association of Singapore.

Therapy services for physical and sensory impairment are currently provided by social service agencies, e.g., the Community Integration Service (CIS) programme for physical disabilities and low vision by AWWA Ltd and the Itinerant Support Service (ISS) by the Singapore Association for the Deaf. Therapy support services are also provided for school-age children and youths by Rehabilitation and Psychology departments in several hospitals, e.g., the KK Women's and Children's Hospital, National University Hospital, Changi General Hospital, and Khoo Teck Puat Hospital.

## Special Education (SPED) Schools

SPED schools are generally categorised as Autism specific schools (admitting only children and youth with Autism) or Non-Autism specific schools (admitting children and youth with or without Autism).

Autism specific schools that cater to those with Autism without intellectual disabilities (Full scale IQ above 70) are Pathlight schools and St Andrew's Mission School. Autism specific schools that cater for those with Autism and intellectual disabilities includes Eden school and St Andrew's Autism School.

The non-Autism specific schools are categorised based on those primarily catering to children with mild intellectual disabilities (Full scale IQ 50-70), e.g., APSN schools, Grace Orchard school, and Metta School, or for children with moderate to severe intellectual disabilities (Full scale IQ 35-49 for moderate, or less than 35 for severe), e.g., MINDS schools.

The schools that accept children with multiple disabilities are AWWA schools, Rainbow centres, and CPAS schools, whilst those who accepts children with sensory impairments are the Canossian School for hearing loss and the Lighthouse school for visual impairment and hearing loss.

Children in special schools may receive transport concessions or subsidies for school bus and public transport travel. These schemes are administered by SG Enable.

## Special Student Care Services

Special Student Care Centres (SSCCs) provide before and after school care services to Special Education (SPED) school-going students with disabilities aged 7-18. The care services could also include educational support and social and life skills for independent living. There are currently eight SSCCs providing for children and youth with Autism Spectrum Disorder, Global Developmental Delay or Intellectual disability, Physical disability, and sensory impairment.

## Health and Dental Needs

In general, the Health Promotion Board (HPB) provides health services for children and youth with disabilities in mainstream and SPED schools similar to typical children through the School Health Services (SHS) (screening, immunisation) and Student Health Centre (SHC) (general clinic services, nutritional support, immunisation, and refraction clinics). Similarly for dental services, it is provided through the Student Dental Centre (SDC), School Dental Clinics, Mobile Dental Clinics, and the Youth Preventive Dental Service (YPDS).

However, caregivers of children and youth with more severe challenges have expressed difficulty accessing these health services provided by HPB. As such, several social service agencies have stepped forward to provide more customised community health and dental services for children and

youth with disabilities. This includes the Mount Alvernia Outreach Clinic, MINDS Clinic, and Tzu Chi Free Clinics. The Tzu Chi dental team collaborates with MINDS to provide on-site dental treatment in MINDS clinic. The MINDS clinic at MINDS hub also provides screening for vision and general health screening.

## **YOUTH MENTAL HEALTH**

Mental health services are largely under MOH's governance, provided by the Institute of Mental Health and Agency for Integrated Care (AIC) in collaboration with social service agencies. Through the National Mental Health blueprint in 2007 and Community Mental Health (CMH) Masterplan in 2012, the Agency for Integrated Care has worked with social service providers to set up 41 community outreach teams and increased mental health services in 12 polyclinics.

### **IMH Services**

For youths with mental health issues in school, the REACH (Response, Early intervention, and Assessment in Community mental Health) programme has been in place since 2007. This is a community-based mental healthcare service for students with emotional, social, and/or behavioural issues. The REACH team is multi-disciplinary, and comprises psychiatrists, clinical psychologists, medical social workers, occupational therapists, and nurses. They work closely with school counsellors from MOE and personnel from Social Service Agencies (SSAs) to provide mental health support in the community.

The Community Health Assessment Team (CHAT), started in 2009, provides community-based assessment and outreach in a centre located in SCAPE, which is a youth-friendly and easily accessible location in the heart of Singapore's retail district. Through its programmes targeting young persons aged 16-30 years, CHAT aims to increase Awareness of mental health issues, Access to mental health resources, and to provide confidential and personalised mental health Assessments. Its three key programmes include 1) webCHAT, an online screening programme; 2) CHAT Supportive Interventions (CSIs), which is an on-site counselling service delivered by certified solution-focused therapy practitioners; and 3) the CHAT Ambassadors Programme, which is a volunteer-based youth participatory group for individuals aged between 16 and 30 years. The ambassadors are young people who have demonstrated an openness towards collaborating with fellow youths and are passionate about improvement of youth mental health service and advocacy work.

Suicide prevention is increasingly an area of urgent and intense work. Many helpful resources and services have sprung up, including MindSG in Healthhubs, which provides information on self-help tools, text-based services, and helplines, as well as chatbots, e.g., Belle, the Beyond the Label helpbot, which is an interactive platform for users to find mental health resources and services in a private and convenient manner.

Another important initiative is the provision of the Graduate Diploma in Mental Health for primary care physicians to upskill their mental health knowledge and practices, as well as the Mental Health-General Practitioner Partnership (MH-GPP) programme. There are now more than 200 general practitioners equipped to support youths with mental health challenges in primary care settings through these programmes.

### **AIC-Administered Services**

The Community Resource, Engagement, and Support (CREST) and Community Intervention (COMIT) teams are provided by social service agencies. CREST is a community-based team aimed at engaging and outreach to people with/at risk of depression, dementia, and other mental health conditions, and provide support to their caregivers. When identified to require community mental health interventions, the Community Intervention Team (COMIT) can be activated to provide community-based multidisciplinary mental health support for clients with mental health and their caregivers so that they can remain in the community for as long as possible. The COMIT team is an allied health-led team made up of counsellors, occupational therapists, psychologists, nurses, and programme coordinators.

## **COMMUNITY SUPPORT FOR FRIENDSHIP AND LEISURE**

### **For Visible Disabilities**

Several community youth bodies and social service agencies have initiated outreach programmes through group-based social and leisure activities, often supported by youth volunteers. These include MINDS Me Too! Club, Rainbow Centre's YAA! And Connected Communities services, and YMCA's Youth Support for Special needs. Several ground-up initiatives and social enterprises also run hobbies and vocational-based programmes for children and youth with disabilities. These are collated in CaringSG's free resource listing for caregivers and the public.

Under the plans for EMP2030, MSF is piloting the Enabling Service Hub (ESH). The ESH, recently launched by SG Enable in collaboration with disability agency SPD in August 2023, offers a place for those with disabilities to engage in social activities and take up courses to learn new skills. The ESH aims to foster inclusion by organising activities for residents both with and without disabilities to come together, while also providing caregivers respite by providing drop-in care services.

### **For Psychosocial Disabilities**

The Supporting Youth in Community (SYiNC) programme is a pilot project by the President's Challenge and the Institute of Mental Health (IMH) to boost community-based support for youths (aged 13-19 years old) with mental health conditions. SYiNC will see IMH teams from CHAT programme training and supporting Social Service Agencies

(SSAs) to provide intervention and psych-social support to youths who are receiving outpatient care at IMH, had been seen at the IMH Emergency Service, were recently discharged from an inpatient stay in IMH, or referred by the IMH REACH team. The four SSAs that are piloting this programme with IMH are Club HEAL (Youth Mental Health @ Club HEAL), Singapore Association for Mental Health (Youth Reach), Singapore Children's Society (Oasis for Minds Services), and TOUCH Community Services (Youth-Clusion). These SSAs programmes run arts, sports, outdoors, and interactive activities for leisure and peer support, e.g., SAMH's C'SAY programme.

## FAMILY SERVICES

Across all ages, family services such as Social Service Offices, Family Service Centres, Child and Youth protection services (e.g., the Child Protection Specialist Centres), and Family violence specialists (e.g., PAVE, NAVH) are largely under the governance of MSF.

### Social Service Office

The 24 Social Service Offices (SSOs) administer Government financial assistance schemes and support individuals and families with customised care plans, and referrals to relevant help agencies based on their needs (e.g., job matching and family services).

### Family Service Centres

There are 47 Family Service Centres (FSCs) in Singapore, which are community-based social services that provide support for low-income and/or vulnerable individuals and families with social and emotional issues. Social Work Practitioners at the FSCs provide case management support and partner with other agencies to coordinate holistic support for clients to help them achieve stability, self-reliance, and social mobility. FSC services include:

1. Information and Referral: Providing information about social services and linking individuals and families to appropriate social services and community resources based on the assessed needs
2. Casework: Providing holistic case management and individual/family counselling
3. Group Work: Bringing individuals and families with common needs together for purposeful group interactions to address their concerns and bring about positive change
4. Community Work: Tapping on community resources to help individuals and families support and empower one another

### Protection Services

Child Protection services include the Child Protection Services (CPS), who are officers from MSF, and the Child Protection Specialist Centres (CPSCs) operated by social service agencies to provide child-centric, family-focused,

and community-based support to children who face abuse or neglect at home. Support provided includes safety planning, casework intervention, counselling to address the risks posed to the children and young persons, and practical and other relevant services to the children and young persons and their families. There are currently two CPSC provided by Big Love Child Protection Specialist Centre and HEART@Fei Yue.

At the moment, there is no direct legislation to protect the rights and welfare of PWD. However, there are related constitutions that support the provision of social services for protection of these individuals. These include the:

- **Vulnerable Adult Act 2018.** The VAA is an act to make provision for the safeguarding of vulnerable adults from abuse, neglect, or self-neglect, and to provide for matters connected with those.
- **Children and Young Persons Act 1993.** The CYPA is an Act to provide for the welfare, care, protection, and rehabilitation of children and young persons who are in need of such care, protection, or rehabilitation, to regulate homes for children and young persons, and to consolidate the law relating to children and young persons.
- **Women's Charter 1961.** The WC is an Act to provide for marriages and the protection of family, the maintenance of wives, incapacitated husbands and children, and the punishment of offences against women and girls. As caregivers in the family are often female, this act can protect women and girls against family violence.
- **Mental Health (Care and Treatment) Act 2008.** An Act to provide for the admission, detention, care, and treatment of mentally disordered persons in designated psychiatric institutions.
- **Mental Capacity Act (Chapter 177A, 2008).** An Act to make new provisions relating to persons who lack capacity and to provide for matters connected therewith. This act is the basis for legal processes such as the appointment of Deputy(s) for young adults without mental capacities who are aged 21 years and above to look after their welfare and matters.

## CAREGIVER SUPPORT

Caregiver support is a new area that has evolved rapidly in the last five years, partly spurred by the COVID-19 pandemic. The importance of strengthening support for caregivers was also highlighted during Emerging Stronger Conversations & Conversations on Singapore Women's Development.

For caregivers of persons with visible disabilities, caregiver support services are overseen by the SGenable under MSF. For persons with psychosocial disabilities, support for caregivers is administered by the Agency for Integrated Care (AIC) under MOH.

**For Visible Disabilities**

The development of the Caregiver Action Map by SG Enable in collaboration with SSAs, hospitals, and Institute of Policy Studies in 2019 expounded on the need to develop services that are user-centric, ecosystems to promote self-help and peer support, and last but not least build inclusive neighbourhoods in the community.<sup>34</sup>

Building on these cumulative efforts, an Alliance for Action for Caregiver of persons with disabilities were convened in July 2021 to implement programmes that improve self-help and peer support, as well as build inclusive communities. The 3i programmes of CSG are the key programmes under the Alliance for Action for caregivers of persons with disability and includes the following:

1. CAREconnect programme to connect caregivers to caregivers and the community
2. CAREbuddy programme to provide 1-to-1 peer support by caregiver volunteers

3. CAREwell programme by professionals to provide transdisciplinary case management support through a keyworker system

In the latest Enabling Masterplan 2030, Area 7 on Caregiving Support targets that by 2030, caregivers of PWD have access to caregiving support, including respite services and future care planning. Access would cover a variety of factors such as awareness, ease of application, affordability, perceived quality, capacity, and suitability of services.

**CAREGIVER EDUCATION AND TRAINING**

The evidence base for the effectiveness and benefits of Caregiver Education and Training (CET) have increased tremendously over the past two decades.<sup>35-42</sup> CET is provided by the SSAs where the child is receiving early intervention services as an integral component of the programme. This family-centred approach is less utilised in school-age services under MOE, though this is increasingly being looked into as well.

# Caregiver Action Map

Caregivers to persons with disabilities perform many vital and crucial roles. The responsibilities and challenges they face in caregiving can often be overwhelming. Caregivers who are aging or have complex needs are more vulnerable to these challenges.



It is this exigency – caring for the caregivers – that gave rise to the Coalition of Partners for Caregiver Support.

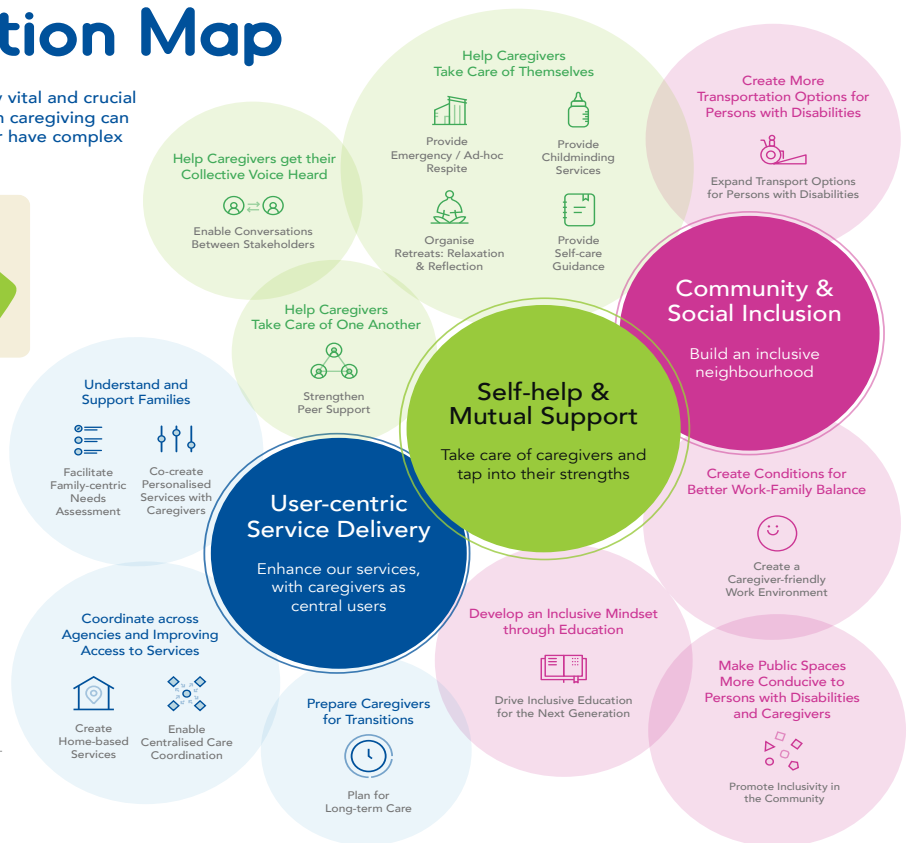
SG Enable, supported by the Institute of Policy Studies, worked with the Coalition of Partners represented by 25 community partners, social service agencies and hospitals to conceptualise a holistic Caregiver Action Map for enhanced caregiver support.

This Caregiver Action Map highlights how we can collectively come alongside caregivers to empower, improve and transform the caregiving journey for those with loved ones with disabilities.

Explore more than 60 ideas to start supporting caregivers today.



Together with The Coalition of Partners for Caregiver Support  
Scan the QR code or click here for the list of Coalition Partners.



## Caregiver-to-Caregiver Support

Several caregiver-specific ground-up initiatives are directed at caregivers as the main beneficiaries. This includes CaringSG (CSG) for caregivers of persons with disabilities and the Caregiver Alliance Limited (CAL) for caregivers of persons with mental health conditions and elderly issues. Caregiver-to-caregiver training and caregiver support groups are provided by CSG's Step One Programme and CAL's C2C (in collaboration with MINDS) Programme. These support programmes are also different from CET in that they are not bounded by where the child is receiving services.

## Service Coordination and Case Management

The SG Enable, a charity supported by MSF, is Singapore's focal agency for administering, coordinating services for PWD and one-stop information center for disability matters. The Service Coordination and Advisory (SCA) team receives referral from the community for any PWD who encountered challenges in assessing publicly funded and community based disability services.

The Disability Case Management Programme (DCMP) offered by MINDS is a holistic case management service that also provides specialised interventions to persons with intellectual and/or developmental disabilities with complex or high-support needs. The DCMP offers intensive case management by social workers, multi-disciplinary and disability-specialised interventions, support by allied health professionals, and family-centric interventions including emotional support, practical coaching, and psychoeducation for families and caregivers to develop appropriate care plans and to better address the immediate needs of persons with disabilities. It also offers case coordination services to bridge persons with disabilities and their families to suitable disability programmes, social services, or community resources.

The CaringSG CAREwell keyworker support programme uses an ecological and routine-based approach to conduct detailed family ecosystem analysis and functional needs assessment for caregivers and their dependents so as to develop functional goals (family goals, dependent-related family goals, and dependent goals) and an individualised family support plan (IFSP). The keyworker supports the caregiver and family members to achieve the functional goals through active service coordination and service integration to optimise and mobilise necessary social and health services.

## For Psychosocial Disabilities

Support for caregivers of persons with mental health conditions is under the ambit of AIC. Several SSAs also provide caregivers of persons with MHC with support. These include the SAMH and ClubHeal.

## USEFUL DIRECTORIES AND RESOURCES

Several online service navigation guides have been developed by SG Enable and AIC to help PWD and their caregivers navigate the complex health and social service landscape. Several key ones and useful resources are listed here:

1. SG Enable's Enabling Guide
2. <https://www.enablingguide.sg/>
3. AIC's e-care locator
4. [https://www.aic.sg/care-services/e-care-locator?gclid=Cj0KCQjwiIOmBhDjARIsAP6YhSVU2X1Q6VMzVXRlpgcCXk3odRKTngybjTdoZHeHN2ahZAEZhaSWyOMaAkDREALw\\_wcB&gclsrc=aw.ds](https://www.aic.sg/care-services/e-care-locator?gclid=Cj0KCQjwiIOmBhDjARIsAP6YhSVU2X1Q6VMzVXRlpgcCXk3odRKTngybjTdoZHeHN2ahZAEZhaSWyOMaAkDREALw_wcB&gclsrc=aw.ds)
5. MSF's SupportGoWhere and Care Services Recommender
6. <https://supportgowhere.life.gov.sg/>
7. <https://supportgowhere.life.gov.sg/caregiving/support-recommender>
8. Mental health resources
9. <https://www.healthhub.sg/>
10. <https://www.imh.com.sg/CHAT/Documents/Downloads/Children%20and%20Adolescents%20Services%20Sep%202013%20v4.pdf>
11. [https://www.aic.sg/partners/Documents/CMH%20Resources/CCMH%20Program%20Information%20Kit%20Partners%20\(Jun2021\).pdf](https://www.aic.sg/partners/Documents/CMH%20Resources/CCMH%20Program%20Information%20Kit%20Partners%20(Jun2021).pdf)
12. <https://www.healthhub.sg/programmes/186/MindSG/Caring-For-Others/My-Child-Teen-Spot-The-Signs> <https://www.aic.sg/resources/Documents/Brochures/Mental%20Health/Mind%20Matters%20Resource%20Directory%20Listings.PDF>
13. Education resources
14. <https://www.enablingguide.sg/im-looking-for-disability-support/education>
15. [https://www.enablingguide.sg/docs/default-source/default-document-library/sscc-service-matrix.pdf?sfvrsn=57608be4\\_25](https://www.enablingguide.sg/docs/default-source/default-document-library/sscc-service-matrix.pdf?sfvrsn=57608be4_25)

## CONCLUSION

Singapore is a member of the United Nations. We acceded to UNCRC (Convention on the Rights of the Child) in 1995, ratified the UNCRPD in 2013, and are committed to the Sustainable Development Goals 2030. We have many legal and ethical obligations to invest in good healthcare and social support for children and youth with disabilities to optimise their outcomes. Riding on the strong global momentum for inclusion, the disability sector has undergone rapid transformation in the last 15 years through cross-ministerial efforts under the mandate of the past three EMPs. The latest EMP2030 charts Singapore's way ahead concerning disability matters,<sup>43</sup> covering three strategic

themes and 14 focal areas to enable persons with disabilities and their caregivers across all stages of life.

1. Theme 1: Learning – Early years, schooling years, beyond schooling years
2. Theme 2: Living – inclusive employment, inclusive living, assistive technology, caregiver support
3. Theme 3: Connecting – inclusive communication, inclusive transport, inclusive public spaces, inclusive healthcare, inclusive sports, inclusive arts and heritage, inclusive communities.

The primary care sector and family physicians play a critical role in realising the vision of the EMP2030, especially in terms of inclusive healthcare. The WHO recognises that the primary care sector is a key strategic entry point<sup>1</sup> for building an inclusive and equitable healthcare system for PWD. **Figure 2** below, excerpted from the WHO’s Global report on health equity for persons with disabilities, summarises

the framework to advance health equity for persons with disabilities through a primary healthcare approach.

Efforts relating to disability-inclusive healthcare ought to be an integral part of any larger strategic plans made by health ministries, e.g., the Healthier SG initiative, rather than as an afterthought. If primary care is made accessible to PWD, it will benefit the able-bodied fellow residents as well. In addition, essential public health functions need to be integrated with the existing social and educational services. Such transformative efforts will require multi-ministry collective<sup>44</sup> resolve (e.g., the EMP2030), cross-sectoral policy change, and collaborative actions. Finally, people need to be empowered and given skills. For the family physician to effectively support PWD and their families to achieve desired outcomes, the physician will not only need medical knowledge but be acquainted with the epidemiology of disability and the current global direction in terms of healthcare for the PWD, and to know the existing disability-related social and health services.

*N.B. The graphic in the hardcopy SFP journal is incorrect. We apologise for the error.*

**Figure 2: Summary infographic from WHO global report<sup>1</sup>**



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### **LEARNING POINTS**

- **Disability is all around us. As doctors, we have the moral obligations and must be professionally equipped to help these individuals who are most vulnerable in healthcare.**
  - **Children and youth with disabilities receive support from myriad services provided by MOH, MSF, and MOE. Timely and family-centred service coordination is key to realising the best outcomes for these children and youths.**
  - **Caregiver support, education, and training is strategic in improving outcomes for children and youth with disabilities, family outcomes, and community inclusion.**
  - **Health Equity for people with disabilities is best achieved by primary care transformation towards inclusion.**
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