

SG ENABLE AND THE SERVICES AVAILABLE FOR PERSONS WITH INTELLECTUAL DISABILITY IN SINGAPORE

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ABSTRACT

There are an estimated more than 100,000 Persons with Disabilities (PwDs) in Singapore, and these disabilities can include physical, sensory, intellectual disability, and developmental disabilities. The presence of a disability does not only affect the individual themselves but also impacts their caregivers and families significantly. Moreover, the care needs of a PwD often persist throughout their life, and change over the different life stages, leading to various challenges for the PwDs and their families. The Ministry of Social and Family Development (MSF) led the development of the Enabling Masterplans (EMP), which are 5-year road maps that serve to guide the development and support of disability-related services in Singapore. In 2013, MSF also established SG Enable as the focal agency that is the first stop for all disability matters in Singapore. SG Enable currently works closely with social service agencies (SSA) and community partners to provide effective and holistic support to PwDs and their caregivers. This article will outline briefly the different types of disabilities, the needs over the life course, and the role of SG Enable in addressing these needs.

Keywords: Disability, SG Enable, Ministry of Social and Family Development, Caregivers, Families, Community Partnerships

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INTRODUCTION

In Singapore, persons with disability (PwDs) are defined as “those with substantially reduced prospects of securing or retaining places and advancing in education and training institutions, employment, and recreation, due to physical, intellectual, and sensory impairments, as well as developmental needs including Autism Spectrum Disorder.”¹ This is a definition utilised by the Ministry of Social and Family Development (MSF) for their Enabling Masterplans (EMP), which are 5-year road maps that have been established since 2007 to guide the development and support of disability related services.¹⁻³ The EMP cover many areas across different life stages, including early

detection, education, employment, health, infrastructure, transport, and assistive technology, among others. Disability schemes and services seek to recognise and empower PwDs as integral and equal members of our society.

Singapore currently does not have a distinct data base of all PwDs, but it is estimated that there are more than 100,000 PwDs locally. This is a significant number. Furthermore, as disabilities not only affect the individual themselves but also impacts their caregivers and families, the number of lives impacted in reality by the diagnosis of disability is way beyond this 100,000. Moreover, with increasing longevity and an ageing population, the number of PwDs in Singapore will only increase in the years to come. As a result, there is a need to ensure that PwDs can obtain the support they need

across their life spans. In order to ensure there is a coordinated and committed effort to provide this support, SG Enable was established by MSF in 2013 as the focal agency that will be the first stop for all disability matters in Singapore. SG Enable therefore strives to enable social service agencies (SSA) and community partners in providing effective and holistic support to PwD and their caregivers. Concurrently, it seeks to improve the disability employment ecosystem as well as encourage greater disability inclusion by raising awareness, imparting relevant knowledge, and encouraging social innovations.

In this article, a brief description of PwDs and the needs across their life course will be outlined. The role of SG Enable and the services available locally for PwDs will also be shared.

SG ENABLE

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DISABILITY ACROSS THE LIFE COURSE

Disability is a broad term that encompasses impairments present in individuals related to physical, sensory, intellectual, and developmental needs such as Autism Spectrum Disorder (ASD).

Refer to **Table 1** for some examples of the various types of disability.

Type of Disability	Definition	Examples
Physical	Partial or total loss of bodily functions or body parts, Congenital/ Hereditary or Acquired (through accidents or medical conditions)	Feature of muscular dystrophy, cerebral palsy, osteogenesis imperfecta (brittle bone disease)
Sensory	Blind or low vision. Full or partial hearing loss. At times, accompanied by speech impairment	Can be related to congenital conditions and associated with other disabilities
Intellectual	IQ 70 and below Having difficulty grasping concepts, problem solving and in performing daily living activities	Feature of Down syndrome, Prader-Willi syndrome, Williams syndrome
Autism Spectrum Disorder	Complex developmental disorder that affects the brain's normal development. Typically exhibits difficulties in communication and social interaction, sensitivity to sensory stimulation and repetitive behaviour	Can be associated with other syndromes e.g., Fragile X syndrome and with other disabilities

Table 1. Different types of disability

As can be seen in the table above, the various disabilities have different impairments that impact an individual's life in a distinct manner. Consequently, the needs of PwDs are heterogenous and diverse. One size does not fit all, and services will have to be customised.

The support services required for an individual with vision impairment will be very different from what is needed for someone with muscular dystrophy and someone with intellectual disability. This is a key point to note.

Furthermore, the needs of an infant diagnosed with cerebral palsy will be very different from an older child attending a special education (SPED) or mainstream school, and will be very different from what is needed for someone with muscular dystrophy and someone with intellectual disability. This is a key point to note. Furthermore, the needs of an infant diagnosed with cerebral palsy will be very different from an older child attending a special education (SPED) or mainstream school, and will be vastly different from his/her needs when he/she matures into an adult, and then an ageing adult.

An important point to note is that the needs of the growing and ageing PwDs are also closely intertwined with the needs of their caregivers, who also progress across their own life stages over the years. To put this in context, the parents of an infant diagnosed with spina bifida will probably be in their 20s or 30s, and will be juggling caregiving duties together with their careers and financial concerns. However, as the infant grows into an adolescent and then into a middle-aged adult, his/her parents would also have progressed on to their 40s, 50s, and eventually their 60s and 70s. Their roles and responsibilities would have changed over the years, and at various times, they could be caregivers for their adult child with disability, whilst concurrently being caregivers for their spouses, their own ageing parents, and perhaps their grandchildren. All of this while juggling and managing their own personal health and financial needs. The needs of the PwD impacts the lives of their caregivers and vice versa. This close and intertwined relationship needs to be carefully considered when planning services.

With these in mind, it is evident that as needs evolve, services too need to keep up with the changes over the life course. As a result, there is a host of differing services catering to the needs of PwDs and their caregivers across their life span. These will be shared in the next section.

DISABILITY SERVICES IN SINGAPORE

The disability services locally are guided by the life course of PwDs, and can be broadly classified into services for children and those for adults. See **Figure 1** for a diagram of the various services along the life course.

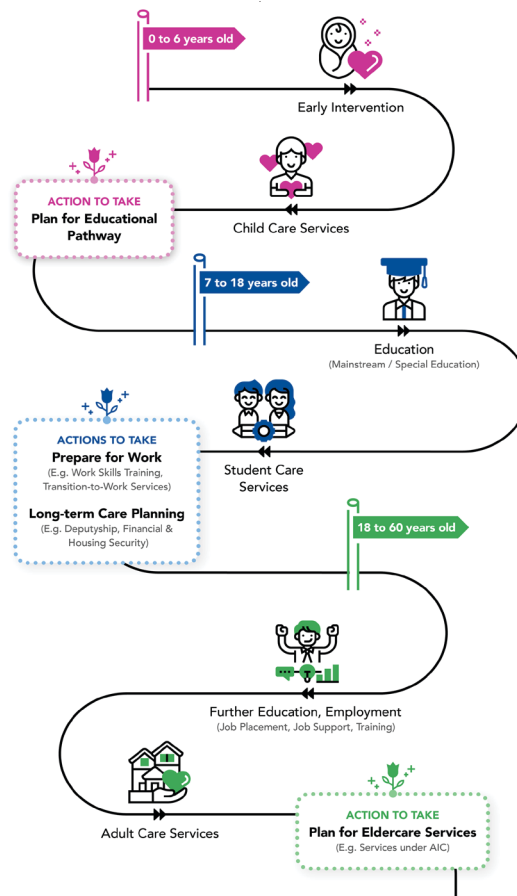


Figure 1. Diagram of the services along the life course of PwDs

Child Disability services are provided for children after detection and diagnosis by the Child Development Units in restructured hospitals or by private paediatricians. Assessments and recommendations are made and children are then referred for early intervention as soon as possible. Thereafter, it is important for families to start planning for the child’s educational pathway together with the schools. Child and after school care services will also need to be considered and planned for.

Some examples of available child disability services include:

- Early intervention programme for infants and children (EIPIC)
- Integrated child care programme (ICCP)
- Inclusive support preschool programme (InSP)
- Pilot for private intervention providers (PIIP)
- Children disability home (CDH)

Adult disability services are provided for students who have completed their education in mainstream or SPED schools or adult PwDs who are not known to services in the community. The transition or cut-off age for PwDs to transfer to adult services is 18 years old. Above 18, the focus for PwDs will become less educational and more vocational.

Some examples of these adult disability services will include:

- Sheltered workshop (SW)
- Day activity centres (DAC)
- Adult disability hostel (AD Hostel)
- Adult disability home (ADH)

Majority of the services mentioned above are located in centre settings. However, not all PwDs are able to access or travel to these centres, and could be unable to leave their homes for various reasons. As a result, services such as home-based intervention services have also been established by a number of SSAs such as MINDS and AWWA with the aim of providing much needed care and engagement for PwDs who are homebound. Furthermore, programmes developed for PwDs should not be limited to those that are only vocational-related, but should also include recreational and physical activities. These are important aspects of an individual’s life and it is essential that these are not neglected. Intentional facilitation to allow PwDs to participate in these may be required as PwDs often face accessibility barriers due to their specific impairments and sometimes also due to challenging family and social circumstances. For example, a PwD with visual and intellectual disability may not be able to travel to and fro for activities independently, but his/her parent may be working full-time as the sole breadwinner and be unable to take time off to accompany the PwD. Without any additional assistance, the PwD will not have

the opportunity to join in these activities even if they are available.

In view of the dependence and reliance PwDs may have on their caregivers, it is evident that the caregivers and families of PwDs are critical in ensuring that they receive the necessary services so as to be able to participate meaningfully in society. Therefore, it is crucial to not only support the PwDs themselves, but to also provide caregivers with the support and resources they require. With these in mind, multiple SSAs have actively developed programmes that aim to address the needs of caregivers, so as to empower and enable them in their caregiving role. Some examples of these programmes will include Rainbow Centre's family empowerment programme, and CaringSG, which aims to bring caregivers together in a common network to support other caregivers. Respite services including customised options are also actively being developed as it is understood that all caregivers will need to take a break from their caregiving roles at intervals and also to tend to their own personal needs.

As can be seen, a variety of services are required to support PwDs and their caregivers in their life course and in their lives together. In the next section, we will highlight the role that SG Enable plays in ensuring that the needs of PwDs and their families are addressed.

THE ROLE OF SG ENABLE

As the first stop for all disability matters in Singapore, SG Enable provides information and referral services to clients, assess their needs, and right-site them for services. It also serves to coordinate referrals across stakeholders for clients who have multiple and complex needs.

The need for such an agency is borne not only out of the many complex challenges that PwDs and their families face, for which they need access, guidance, and support, but is also critical due to the many transition points in the life course of individuals. Services and programmes appropriate for a particular child and family today may no longer be relevant or suitable two years down the road if circumstances change. Such situations could include transitioning from SPED schools to post-18 adult services, seeking employment after leaving their SPED or mainstream schools, switching to a new job, or a change in care situations. It is often during these periods of change that PwDs and their families will require additional support. Particularly with increasing longevity and ageing of caregivers, early conversations on future care plans to discuss what lies ahead if caregivers pass on become more and more important. The death of a caregiver will be an extremely significant event in the life of a PwD and a period of transition and adjustment will follow, during which PwDs will need to be supported in practical and also psycho-emotional aspects. Pre-empting, planning, and then providing support for PwDs and their families through transition periods requires a holistic and integrated approach, and SG Enable's role is to be a one-

stop resource agency that can step in with resources and support in a timely manner.

With coordinated and clear sharing of information, the aim is to empower PwDs and caregivers to make informed decisions and have easy access to resources, referrals, funds, grants, and customised support. In order to make this information even more accessible, SG Enable has established an online portal where The Enabling Guide can be found.⁴ With sections specially tailored for PwDs, caregivers, service partners and also the public, this guide allows individuals to obtain information on what the needs of PwDs are, the services and schemes available, and how they can get help, or conversely, help. This relates to healthcare needs as well, which will be covered briefly in the next section.

CHALLENGES FACED IN ACCESSING HEALTHCARE

PwDs face a number of challenges in accessing services, and one key area is in healthcare. Accessibility, seen in a broader context, does not only refer to being able to get to the healthcare facility physically, but can be defined as having the "the timely use of personal health services to achieve the best health outcomes".⁵ This can refer to having opportunities to identify healthcare needs, to seek healthcare services, to reach, to obtain or use health care services, and to actually have a need for services fulfilled.⁶ Put simply, not being able to make appointments easily or seamlessly clearly results in poor access, but even an individual who gets to a healthcare facility successfully but is unable to have his/her medical needs addressed appropriately also does not qualify as having access.

Take for example a PwD who is visually impaired. He/she may have difficulties making appointments, or may not be aware that his/her queue number is being called, as most information is conveyed via visual platforms. Also, when a PwD sees a doctor, often many of the questions are directed towards caregivers, particularly if the individual has a communication or intellectual disability. This proxy examination, though at times unavoidable, can lead to miscommunication or misdiagnosis, which may result in health needs being inadvertently not addressed. Furthermore, the physical environments of healthcare settings may be too noisy or overstimulating for individuals with sensory processing disorders and/or ASD. History and examination of the individual may consequently be suboptimal as he/she may already be anxious and distressed. This can potentially lead to difficulties with diagnosis and treatment.

The above scenarios are non-exhaustive, and serve mainly as examples of how access to healthcare is often not straightforward for PwDs. This however needs to be addressed. In fact, healthcare access has become an increasingly urgent problem with longer life expectancy in our population, as a longer life span brings with it additional health considerations.

In 2013, Singapore ratified The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which is a “comprehensive convention to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”.⁷ The right to health is a fundamental human right, and it is essential that all effort is made to understand and address the barriers that PwDs face in obtaining good quality healthcare.

WHAT THE COMMUNITY CAN DO

In order to address barriers in seeking services including healthcare, services and partnerships need to be developed and established. With this in mind, SG Enable strives to bring stakeholders and community partners together to raise awareness, form networks, and also co-develop services that can better cater to the needs of PwDs.

From the healthcare perspective, the goal is to be able to equip all frontline officers and healthcare professionals to understand PwDs and their needs, and better serve and support these patients. Customised services may also need to be established for specific population groups.

In order to encourage these important collaborative efforts, SGE conducts consumer-inclusiveness training and consultancy programmes that guide organisations towards greater disability inclusiveness. Using a combination of in-person/virtual classroom-based lecture, experiential activities/demonstrations, and group discussion and presentations, SGE conducts disability-inclusive customer service workshops to help participants gain knowledge about disabilities, understand the challenges and constraints faced by PwDs in their lives, and learn how to interact and communicate with PwDs. With these, participants will be able to better appreciate accessibility considerations and translate this knowledge into practical support when they design their services and programmes.

On top of having opportunities for partnerships, it is also important for community partners and service providers, including healthcare professionals, to have a broad overview of the services available locally and know where to refer PwDs and their families to when they need help. SG Enable is such a platform, and service providers are encouraged to actively connect PwDs and their caregivers to SG Enable if they verbalise any challenges or concerns, so they can get the support they need in a timely manner. There are various channels through which these referrals can be made. Families can be directed to the online enabling guide (www.enablingguide.sg) or enquiries can be made to the concierge who is onsite at the Enabling Village located in Lengkok Bahru, or via their information line (1800 8585 885), or via email at contactus@sgenable.sg.

CONCLUSION

PwDs and their caregivers face many challenges from the point of diagnosis and over their life course. With distinct needs amongst the different disabilities, multiple transition

points and longer life expectancy, services need to be able to cater to the unique and evolving needs of PwDs and their families.

Established by MSF as the first stop agency for disability matters, SG Enable plays a large role in providing information and referral services to clients, assessing their needs and right-siting them for services. It also serves to coordinate and work with community partners to raise awareness, increase knowledge, and ultimately co-create new services that can address the needs of PwDs and their families. Together, the aim is to empower PwDs and caregivers to make informed decisions and have easy access to the resources and support that they need throughout their life course, so as to lead meaningful lives of their choice.

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LEARNING POINTS

- **In Singapore, PwDs are defined as “those with substantially reduced prospects of securing, retaining places, and advancing in education and training institutions, employment, and recreation, due to physical, intellectual, and sensory impairments, as well as developmental needs including Autism Spectrum Disorder.”**
 - **Services need to take on a life-course approach as the care needs of a PwD evolve over the different life stages, leading to various transition points and challenges for PwDs and their caregivers across their life span.**
 - **Established by MSF as the first-stop agency for disability matters, SG Enable plays a large role in providing information and referral services to clients, assessing their needs and right-siting them for services. It also serves to coordinate and work with community partners to raise awareness, increase knowledge, and co-develop new services to address service gaps.**
 - **Service providers and partners in the community are important contact points for PwDs and their families, and all PwDs and caregivers who verbalise care needs should be referred in a timely manner to SG Enable.**
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