UNDERSTANDING THE QUALITY OF LIFE OF ADULTS WITH DISABILITIES
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Before I became President of NCSS, I used to volunteer for a charity, handing out food provisions to vulnerable families. Many recipients were kind and invited me into their homes. What struck me during these visits was the sight of stacks of unconsumed and even expired food. They explained to me that when social service organisations offered help, it was usually food.

While well-intentioned, gifts of food address hunger as opposed to what keeps people hungry. That food goes uneaten and families remain vulnerable tells us that hunger is but one need among many. It also reminds us that people’s real needs can be very different from what we believe them to be.

In addressing these issues, NCSS advocates a quality of life approach to understanding needs. Areas such as psychological well-being, independence and having social support are vital to living well. This entails encouraging people to express what they need, and to be active participants in addressing their own needs.

The Quality of Life Study has shed valuable insights on how all individuals can hold onto their aspirations, use their abilities and be active in society. While we have taken steps towards inclusion for persons with disabilities by improving the infrastructure and opportunities for training and employment, we now need to draw upon their participation and contribution in the journey to further better their lives.

Ultimately, it is my hope that every contributor to this sector can join NCSS in taking a person-first perspective, seeing individuals beyond recipients of help alone and empowering all to live with dignity in a caring and inclusive society.
It must be unimaginable that someone with cerebral palsy could be married with two beautiful children, run his own consultancy firm and complete a kayaking expedition around Singapore to raise funds. Indeed, I would have never achieved these milestones if my mother had sent me to an institution when I was born, on the advice of the paediatrician, as there was “nothing much she could do” – that my life wasn’t worth the effort.

Growing up under preconceived notions remains very much a part of my life. When I was in school, my teachers would constantly advise me not to take P.E. lessons and look after my schoolmate’s belongings instead. I was also told to quit kayaking as a CCA, because I would “injure myself and die out there”.

Even though human beings are made up of countless possibilities, society often fails to look beyond what they see as a disabling condition. As a result, the self-worth of a person with disability takes a beating from young, snowballing over time into a lens of pity, helplessness and resignation, both for the person and the people around him or her.

I hope that the studies presented here will inform service providers and the community towards a vision of empowerment and solidarity, rather than liability. As long as we put in the effort, we will discover beyond a single difference that there are far more similarities which we share. With time, it is my wish that prejudiced lenses will be shed away.

An ideal world is certainly not unreachable. It is simply about being able to perform the everyday tasks that most of us can do, be it shopping for groceries, doing one’s laundry, having friends and romantic relationships and being treated just like anyone else.

The next time you meet a person with a disability, resist the urge to judge what they can do, who they are and how different they might be. Instead, start a conversation about what they want to do, who they aspire to be and most of all, how you can journey with them to achieve it.

As for me, I continue to take life’s challenges in my stride, and strive constantly to lead a meaningful life and to contribute back to Singapore.

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**MESSAGES**

**MR LEO CHEN IAN**

Founder and Partner, Insight N Access Pte Ltd

"As long as we are willing to put in the effort, we will soon discover beyond a single difference that there are far more similarities which we share."

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LEARNING
Cognitive deficits that impact academic achievement.

**DYSCALCULIA**
Difficulties in the reception, comprehension or production of quantitative and spatial information.

**DYSLEXIA**
Difficulty in reading skills such as word reading, comprehension and overall fluency.

**DYSPRAXIA**
Difficulties in movement, balance and coordination that often result in an appearance of clumsiness.

**DYSGRAPHIA**
Difficulty in writing, resulting in work that may be illegible or inaccurately spelt.

SOME TYPES OF DISABILITIES

**PHYSICAL**

**Total/partial loss of bodily function (e.g. walking, motor skills) or a part of the body (e.g. amputation).**

- **MUSCULAR DYSTROPHY**
  An umbrella term for a group of muscular disorders characterised by muscle weakness, wasting and contractures, which are usually progressive in nature and sometimes even life-threatening. These disorders result from inherited gene abnormalities.

- **SPINAL CORD INJURY**
  Injuries to the spinal cord that result often in weakness in both lower limbs (paraplegia) or in all four limbs (tetraplegia) with potentially life-threatening complications.

- **POLIO**
  A viral infection typically recognised by weakness, paralysis or reduced muscle tone.

- **SPINA BIFIDA**
  A birth defect of the spine that manifests in various forms of severity. Spina bifida occulta is the mildest form, having no signs and symptoms or neurological problems. More severe manifestations include meningocele or the potentially life-threatening myelomeningocele (open spina bifida).

- **PARALYSIS**
  The loss of the ability to move (and sometimes to feel anything) in part or most of the body, typically as a result of illness, poison or injury.

- **AMPUTATION**
  Surgical removal of all or part of a limb, an organ, or projecting part or process of the body.

**DEVELOPMENTAL**

**Diverse group of conditions that occur in the developmental period of a child, resulting in difficulties in personal, social, academic or occupational functioning.**

- **AUTISM SPECTRUM DISORDER**
  A range of developmental disorders characterised by difficulties in social interaction, language and social communication as well as flexibility of thought and behaviour. Some examples on the spectrum are Autism, Asperger syndrome and Childhood Disintegrative Disorder.

- **CEREBRAL PALSY**
  A group of non-progressive disorders occurring in young children in which injury to the brain causes impairment of motor function.

- **DOWN SYNDROME**
  A genetic condition caused by the presence of an extra chromosome, it is associated with a range of physical impairments and developmental delays, including delayed motor and cognitive skills.

- **INTELLECTUAL DISABILITIES**
  Having significant limitations in adaptive functioning along with an IQ below 70. It is characterised by impairments in academic and social functioning as well as skills needed for daily living.

Sources: Cerebral Palsy Alliance Singapore, Down Syndrome Association (Singapore), Dyslexia Association of Singapore, Institute of Mental Health, Ministry of Health, Muscular Dystrophy Association (Singapore), National University Hospital, NCSS, NUH Women’s Centre, Singapore National Stroke Association, Society of Rehabilitation Medicine (Singapore).

People, including those with disabilities, are living longer. As the nation faces an ageing population, the number of persons with disabilities acquired from accidents and illnesses is likely to rise. In addition, there will be less familial support for persons with disabilities.

**SENSORY**
When one of the senses – sight, hearing, smell, touch, taste and spatial awareness – is impaired.

**DEAFNESS/HEARING IMPAIRMENT**
The partial or complete loss of hearing in one or both ears. Ranges from moderate hearing loss, in which conversations may be hard to hear, to profound hearing loss where no sound is audible.

**VISUAL IMPAIRMENT**
Moderate to severe visual loss that cannot be corrected to a normal level by medication, operation or the use of optical lenses (e.g. spectacles).

**KEY TRENDS**

**UNDER-18**
More children are being diagnosed with **DEVELOPMENTAL ISSUES**
Increasing numbers of children diagnosed with **AUTISM SPECTRUM DISORDER**

**POST-18**
Rising demand for **LONGER-TERM CARE SERVICES**, as persons with disabilities age and seniors acquire disabilities
Greater demand for quality and diverse service arrangements for persons with **MODERATE TO SEVERE** disabilities

**RESIDENT OLD-AGE SUPPORT RATIO**

Source: Enabling Masterplan 3.
Source: Department of Statistics.
INTRODUCTION

When thinking about disability, attention is often drawn to the condition rather than the person who bears it. From then on, it becomes the primary lens with which needs, and the solutions to address them, are conceived. Subsequently, efforts are focused on rehabilitating the condition alone, which may skim across broader contexts that persons with disabilities are part of.

To meet needs in a more effective, collective and sustained manner, NCSS supports a person-centred and ecosystem approach towards helping individuals achieve quality of life. This is also the value which underlies the Social Service Sector Strategic Thrusts (2017-2021), a 5-year roadmap for the social service sector.3

**PERSON-CENTRED**

A person-centred approach operates on the belief that an individual has the capacity to understand, articulate and work through problems, making decisions on how to overcome them.4

**ECOSYSTEM**

Addressing individuals holistically also means seeing them as enmeshed in different, interrelated contexts that influence every aspect of an individual’s life - an ecosystem5 comprising caregivers and family, community and wider society. In practice, this means that understanding the needs of persons with disabilities necessitates taking into account their interactions with the ecosystem, towards more holistic understanding and solution creation.

**QUALITY OF LIFE**

Taking a multi-faceted approach to individual well-being, an essential outcome is that individuals’ quality of life is optimised in the form of a core set of diverse, essential needs. These needs are evaluated from individuals’ own point of view, which gives credence to peoples’ own awareness of what they need. This is important because researchers agree that the assessment of quality of life is subjective6, and because individuals perceive needs and give importance to them in different ways.

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3 The Social Service Sector Strategic Thrusts document may be found on NCSS' website at http://www.ncss.gov.sg/4ST.
4 The term ‘person-centred’ was first introduced by the psychologist Carl Rogers in the 1940s. Further information about the person-centred approach can be found at http://adpca.org/content/history-0.
An individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

It conceptualises Quality of Life in six constituent domains, subdivided into 24 facets. More details on the domains and facets may be found in Annex A. 

The World Health Organisation defines Quality of Life as such:

QUALITY OF LIFE STUDY ON PERSONS WITH DISABILITIES

INTRODUCTION
In 2016, NCSS completed the Quality of Life Study on persons with disabilities in Singapore, a nationwide survey which sought to ascertain what areas they felt contributed most to their well-being and could be improved upon. It is the first large-scale quantitative study that highlights what persons with disabilities themselves consider important to their well-being.

Collectively, these findings support existing knowledge and feedback, and will help the sector in deeper research, service planning efforts, public education and policy recommendations. In particular, the latest Enabling Masterplan, a 5-year roadmap that guides initiatives for the disability sector, adopted both the Quality of Life framework and findings in its strategic directions and recommendations.

The results from this inaugural study serve also as a baseline for future comparison, allowing changes in quality of life to be tracked over time. This helps social service stakeholders to assess the impact of their initiatives and identify trends for future planning.

RESEARCH OBJECTIVES

- To identify the needs of persons with disabilities from their perspective, across six domains of quality of life.
- To obtain a quantitative baseline for the quality of life for persons with disabilities.
- To surface priority areas for intervention.

METHOD
Participants were obtained through random sampling from SG Enable’s database, and administered a survey face-to-face which they had to complete by themselves as far as possible. The final sample comprised 981 responses. Respondents were asked to complete the survey on their own (with clarifications where necessary), failing which a proxy (main caregiver) answered on their behalf.11

KEY DESCRIPTIVES

3.4% of Singaporeans aged 18 to 49 have a disability*.
49% have a moderate to severe disability.
2.1% of students aged 7 to 18 have a disability.
55.6% have a chronic disease (e.g. heart disease, diabetes, stroke and asthma).*
13.3% of Singaporeans aged 50 and above have a disability*.
12.6% have a mental health condition.
30.4% have >1 disability type.


More details on the domains, and facets under each domain, in Annex A.

* Findings are self-reported.
* Includes those who acquired disabilities from accidents and illness.

10 Source: Ministry of Education. Based on number of reported cases of students with sensory impairment, physical impairment, Autism Spectrum Disorder and intellectual disability. The total student population is put at approximately 460,000.

11 Respondents were allowed to indicate their attendance of more than one service.
As a basis for comparison, NCSS also obtained a representative sample (n = 942) of the general population through the Department of Statistics. In this survey, three World Health Organisation Quality of Life (WHOQOL) instruments were used. Further questions were asked on their satisfaction of services accessed, the types of services they would like as well as the Quality of Life domains in which they desired the most improvement. All items were translated into Chinese, Malay or Tamil where necessary.

12 Responses from the general population sample which indicated that they had mental health conditions or disabilities were removed so that the general population sample could be used as a control group for comparison with the other target groups. 1,400 surveys sent out. Response rate: 67.3%.

13 According to WHOQOL Group (1998), the WHOQOL-BREF has been validated cross-culturally for various populations worldwide. An example may be found on the WHO’s website at http://www.who.int/mental_health/media/en/76.pdf.

14 Items were generated from focus group discussions, tested and validated across 15 countries (Power, Green & The WHOQOL-DIS Group, 2010).

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**WHOQOL-BREF**

This is a 26-item scale that asks respondents to rate their state of well-being in the last two weeks. Questions are answered on a five-point scale, and comprise:

- 24 facet-level questions that correspond with six domains of Quality of Life
- Two questions that ask about perception of life and health overall

In addition to the sample of persons with disabilities, the WHOQOL-BREF was administered to that of the general population as well.

**WHOQOL-DIS**

An add-on module of WHOQOL-BREF that surveys respondents on three areas of life regarded as important to persons with disabilities – Autonomy, Discrimination and Social Inclusion. Similarly, questions were answered on a 5-point scale and based on respondents’ experiences in the last two weeks. There were 13 questions in total, including:

- One question asking about the effect of the disability on one’s life overall
- 12 questions on aspects of Autonomy, Discrimination and Social Inclusion, including:

**OTHER A REAS SURVEYED**

**BY NCSS**

<table>
<thead>
<tr>
<th>Facet</th>
<th>Areas Covered</th>
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Being able to make day-to-day choices and big decisions in life |
| Discrimination | Unfair treatment  
Needing to stand up for oneself  
Worries about the future |
| Social Inclusion | Feeling accepted and respected in society  
Ability to communicate effectively with people  
Opportunities to be involved in social and local activities  
Feeling that dreams, hopes and wishes will be realised |

**RESPONDENT BREAKDOWN BY EMPLOYMENT AND DISABILITY TYPE**

- Open Employment
- Sheltered Workshops
- Accessing Education/Day Activity Centres
- Others
- None

**RESPONDENT BREAKDOWN BY EDUCATION**

- None 12.2%
- Polytechnic 4%
- Primary School 17.2%
- Secondary School 13.3%
- University Degree Holders 42.1%
- Institute of Technical Education 4.8%
- Others 0.6%
- Junior College/Pre-University 1.6%

**COMPARISON TO THE GENERAL POPULATION**

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**WHODAS 2.0 (WHO DISABILITY ASSESSMENT SCHEDULE)**

This 36-item instrument measures functioning levels in six domains of health and disability. Responses are indicated on a five-point scale to measure intensity and extent of respondents' difficulty in performing these activities:

**Domain** | **Areas Covered**
---|---
Cognition | Understanding and communicating
Getting Along | Interacting with other people
Life Activities | Domestic responsibilities, leisure, work and school
Mobility | Moving and getting around
Participation | Joining in community activities, participating in society
Self-Care | Attending to one's hygiene, dressing, eating and staying alone

**Key Findings**

**Finding #1**

Persons with disabilities experienced a lower quality of life than the general population.

It was even lower for persons with disabilities who had complex needs (i.e. having a disability or being over the age of 65).

**Finding #2**

Persons with disabilities scored lower than the general population across all quality of life domains\(^1\), especially on level of independence, personal beliefs and social relationships, particularly in the area of social support from friends.

\(^1\) The WHODAS 2.0 has been tested in different cultural settings and health populations and has robust psychometric properties (Gold, 2014).

\(^{**} p < 0.01. A Multivariate Analysis of Variance was performed on the six domains related to quality of life (DV) and group membership (IV).\)

For more information on the Quality of Life domains and facets, please refer to Annex A.
When asked about which areas they wished to see improved, persons with disabilities prioritised level of independence, followed by psychological well-being and in their environmental resources.

Regardless of disability type, persons with moderate-severe disabilities experienced lower quality of life than those with mild disabilities.

Persons with disabilities felt that they lacked autonomy and control over their lives and in life decisions. They also felt excluded from contributing meaningfully to society, and did not feel that they could fulfil their personal potential.
24-year-old full-time national serviceman Samuel aspires to find work in the financial sector and boost his employability by earning a degree. Having had positive working experiences with Mount Alvernia Hospital and in the Air Force, he sums up his thoughts about how persons with disabilities can be better included in society:

“Having an inclusive society means that everyone is given an equal opportunity to have a try on what they want to do, and that their contributions are recognised. As long as people contribute to society, we shouldn’t care about how they look like, nor their disabilities. We [should] just recognise what they do.”

**Finding #7**

Respondents were more likely to have a lower quality of life if they had:

- A chronic disease (1.8x)
- Moderate to severe functioning level (4.7x)
- No main daily activity, e.g., employment, Day Activity Centre (1.7x)
- Not been earning a personal income (1.7x)
- Not participated regularly in sports or physical recreational activities (1.6x)

Only 39% of all respondents participated in sports or physical recreation at least once a week.

**Finding #8**

In holistically improving the areas outlined in the WHOQOL-BREF, addressing social inclusion when designing initiatives can achieve the greatest effect.

Aspects to focus on include:
- Eliminating barriers to understanding, communicating and getting along with others
- Increasing social participation

Hence, for instance, programmes to improve work capacity could focus on imparting relevant skills to better manage interpersonal relations.

**A Structural Equation Modelling (SEM) is used to understand the relationship between factors, particularly that between observable and unobservable variables. It provides numerical estimates that indicate the strength of such relationships.**

<table>
<thead>
<tr>
<th>PERSONS WITH DISABILITIES: STRUCTURAL EQUATION MODELLING</th>
<th>Quality of Life of Persons with Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHOQOL-BREF</td>
<td>Quality of Life of Persons with Disabilities</td>
</tr>
<tr>
<td>Autonomy</td>
<td>0.48</td>
</tr>
<tr>
<td>Social Inclusion</td>
<td>0.33</td>
</tr>
<tr>
<td>Discrimination</td>
<td>0.10</td>
</tr>
<tr>
<td>WHOQOL-DIS</td>
<td></td>
</tr>
<tr>
<td>Autonomy</td>
<td>0.30</td>
</tr>
<tr>
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<tr>
<td>WHODAS 2.0</td>
<td></td>
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<tr>
<td>Getting Around</td>
<td></td>
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<tr>
<td>Household Activities</td>
<td></td>
</tr>
<tr>
<td>Self-Care</td>
<td></td>
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</tbody>
</table>

* Binary logistic regression was conducted (median QOL cutoff). Controlled for age and gender. Lower quality of life refers to scores in the bottom 50th percentile.

* A simplified representation of Structural Equation Modelling – Multiple Indicators Multiple Causes Method.
Finding #9

Persons with disabilities who were not engaged in a main daily activity, particularly employment, experienced lower quality of life.

They reported diminished psychological well-being, social relationships and sense of meaning in life.

Finding #10

Those in employment reported a higher level of independence.
However, those in open employment tended to feel discriminated against.

Several faced interpersonal issues as well, though this was not limited to employment alone.

Many were not engaged in any activities even if they were higher functioning (e.g. can move, get around by themselves, can care for themselves, can communicate well), could care for themselves and were able to communicate well.
NEEDS ASSESSMENT ON RESPITE CARE FOR CAREGIVERS OF PERSONS WITH DISABILITIES

INTRODUCTION
Caregivers are often the main pillars of support for persons with disabilities. As instrumental agents in the latter’s quality of life, they have a direct impact on the well-being of care recipients. While they play a crucial role in the disability support ecosystem, little research has been done on these individuals, nor on their respite care needs. It is important that we understand caregivers better as they bear tremendous responsibilities that affect their own lives – and those of their care recipients – in equally consequential ways, be it higher levels of guilt or worry, stress or decreased work participation in general.

Following up on feedback received during the Enabling Masterplan 2 (2012-2016) as well as that obtained from caregivers and members of the public, NCSS conducted a study to understand the respite care needs of caregivers of persons with disabilities. Comprising both a survey and focus group discussions, it sought to unearth caregivers’ understanding of respite care, their views and preferences of respite care services as well as their need for such services in relation to various predictors (e.g. stress levels, characteristics of care recipients).

Findings of the study revealed suggestions to alleviate caregiver stress. In particular, these recommendations informed the Enabling Masterplan 3, and it was announced in the Singapore Budget 2017 that the government would set up a disability caregiver support network to provide information, planned respite, training and peer support, and work together with social service organisations to strengthen caregiver support for caregivers of people newly diagnosed with disabilities.

RESEARCH OBJECTIVES
• To unearth caregivers’ understanding and views of respite care
• To ascertain their need for such services in relation to various predictors (e.g. stress levels, characteristics of care recipients)

METHOD
This assessment comprised a quantitative survey as well as pre-survey focus group discussions.

FOCUS GROUP DISCUSSIONS
Six focus group discussions were held with caregivers of pre-schoolers with special needs (0-6 years), students (7-21 years) and adults (21 years and above). Each session had five to six participants, totalling 33.

The discussions captured ideas of what respite care meant to caregivers, existing service gaps, services received and the adequacy of services in meeting caregiver needs. These inputs went into the subsequent quantitative survey, which concentrated on gathering data on the profile of caregivers and their care recipients, current knowledge of respite care and preference for respite care services.

QUANTITATIVE SURVEY
Social service programmes were stratified first according to the various age groups served, and then by service type. Random sampling was then carried out on each stratum. Based on calibrated numbers, a total of 1,600 surveys were distributed. The achieved sample size was 789.

16 A caregiver is an individual who assists others with medical tasks and activities of daily living. Formal caregivers perform this role in institutional settings, while informal caregivers, usually unpaid, care for others at home, in public and other more informal settings.
17 Storch et al. (2009) found that caregivers who are often very personally attached to the care recipient suffer from strong feelings of guilt and worry, stress or decreased work participation in general.
18 Goh, Chong & Chan (2010) noted that 54% of parents with children in Early Intervention Programmes for Infants and Children (EIPIC) experience clinically significant levels of stress.
CAREGIVER SUPPORT SERVICES ACCESSED

<table>
<thead>
<tr>
<th>Service</th>
<th>Accessed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Support</td>
<td>14</td>
</tr>
<tr>
<td>Caregiver Training from Hospitals</td>
<td>21</td>
</tr>
<tr>
<td>Others</td>
<td>43</td>
</tr>
<tr>
<td>Home Help Services</td>
<td>44</td>
</tr>
<tr>
<td>Religious Support Groups</td>
<td>62</td>
</tr>
<tr>
<td>Caregiver Programmes from Social Service Organisations</td>
<td>64</td>
</tr>
<tr>
<td>Mutual Help/Support Groups</td>
<td>102</td>
</tr>
<tr>
<td>Counselling</td>
<td>149</td>
</tr>
</tbody>
</table>

CARE RECIPIENT’S DISABILITY TYPE

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Impairment</td>
<td>13%</td>
</tr>
<tr>
<td>Sensory Impairment</td>
<td>3%</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>32%</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>29%</td>
</tr>
<tr>
<td>Multiple Disabilities</td>
<td>22%</td>
</tr>
</tbody>
</table>

SEVERITY OF CARE RECIPIENT’S DISABILITY

<table>
<thead>
<tr>
<th>Severity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>39.4%</td>
</tr>
<tr>
<td>Moderate</td>
<td>49.1%</td>
</tr>
<tr>
<td>Severe</td>
<td>11.5%</td>
</tr>
</tbody>
</table>

The survey probed into respondents’ caregiving and care recipient profiles as well as their knowledge, perception and utilisation of respite care. Three instruments were also included in the questionnaire.

CAREGIVER STRAIN INDEX (CSI)26

A 12-question tool measuring strain related to care provision, the CSI is used to assess individuals on the following domains affecting well-being: Financial, Employment, Physical, Social and Time. Positive responses to 7 or more items indicate a high level of strain that may warrant clinical attention.

GENERAL HEALTH QUESTIONNAIRE-12 (GHQ-12)27

In this tool, 12 questions are asked that identify common psychiatric conditions in both clinical and general populations. It assesses the severity of mental disturbances over the past few weeks on a 4-point scale (from 0 to 3), with a higher score representing greater levels of mental distress.26

KESSLER-6 (K6)29

Developed for use in the US National Health Interview Survey (NHIS), K6 comprises six questions on a scale of 1-5, to distinguish cases of serious mental illness from non-cases. A case would be defined if the sum of all six items is greater than or equal to 13.

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26 From Robinson (1983). More information on the scale can be found at https://consultgeri.org/try-this/general-assessment/issue-14.pdf. The CSI has been found to be internally consistent when used with different family caregivers (Blake et al., 2003; Khan et al., 2007). In this study, Cronbach α = 0.87.

27 From Goldberg & Williams (1988). The GHQ-12 is known for its brevity and use in clinical settings and has been translated and validated in at least two languages in addition to English. It has been found to be psychometrically viable in countries as diverse as Germany (Romppel, Braehler, Roth & Glaesmer, 2013), Spain (Sanchez-Capdevila & Dresch, 2008) and Iran (Montazeri, Harirchi, Shariati, Garmaroudi, Ebadi & Fateh, 2003). More information on the scale can be found at http://www.psicothema.com/pdf/3564.pdf. In this study, Cronbach α = 0.93.

28 A 0-1 re-scoring also provides a total score, for which a 3-4 cut off point is commonly used to indicate caseness.

29 A translation of K6 (Kessler et al., 2002). More information on the scale can be found at https://www.gem-measures.org/public/DownloadMeasures.aspx?mid=35In this study, Cronbach α = 0.91.

Caregivers were allowed to select more than one service.
KEY FINDINGS

Finding #1

Close to half of caregivers of persons with disabilities experienced caregiver strain, with 4 in 10 being psychologically distressed.

More than 6 in 10 felt burdened by the weight of their caregiving duties.

Petrina is mother to 17-year-old Jayden, who has Autism Spectrum Disorder. As a freelance editor, she home-schools Jayden, and faces many challenges caring for him on a daily basis. She has had to borrow money from her father to get by. Jayden is also often aggressive, be it with her or other people. As a result, she experiences what she terms as “stress and tension” on a daily basis.

“I’ve had a stressful episode where my son attacked me for about less than one minute. Do you know what it feels like to be attacked by somebody bigger than you, someone you have been taking care of? He’s grabbing at you, kicking you… It only happened for less than a minute, but it will take a few days for the scars to recover. Every time I pick up my shirt or my handbag, it’s going to hurt my back because of the way he attacked me.”

Finding #2

Factors Contributing to High Caregiver Stress

1. Disability of care recipient is severe
   - Average Caregiver Strain Index Score (CSI):
     - Mild: 4.8
     - Moderate: 6.5
     - Severe/Profound: 8.2

2. Care recipient is young
   - Average Caregiver Strain Index Score (CSI):
     - 0-6: 7.2
     - 7-21: 5.7
     - Above 21: 5.9

3. Presence of chronic illness in either caregiver or care recipient
   - Average Caregiver Strain Index Score (CSI):
     - No Chronic Illness: 5.6
     - Either or Both have Chronic Illness: 7.6

4. Care recipient has Autism Spectrum Disorder or intellectual disability

5. Low average household income

6. High education

“Maybe I was still in a denial stage, I cannot understand that he has this problem ‘cause he looks so normal… that’s the thing I cannot accept…”

Caregiver of child with Autism Spectrum Disorder
Having a degree did not shield Anne from the struggle of caring for her son, 7-year-old Cody. She treasures spending time together with Cody, whether at picnics, running and biking, or bringing him to parties where she frequently tells family and friends about him. However, there was a time when she had high hopes for her first son – hopes that were crushed after he was diagnosed with Autism Spectrum Disorder.

“The first year was difficult for me. ‘Cause he was my oldest son so when he came I was very idealistic… I want to be a perfect, cool mum… and then when we found out that he had Autism the world crumbled. Within a year, we were so busy with therapies and trying to learn everything that I closed off. I think [that] my coping [period] was one year, after that I came out publicly, talked about it on Facebook, Twitter, what have you. I advocate for people with disabilities. I fight for people who don’t understand… I tell everybody about him, and for me it helped a lot.”

Finding #3

Contrasts with the Singapore Survey on Informal Caregiving (Chan, Ostbye, Malhotra & Hu, 2013), which observed that caregivers of elderly care recipients experienced less stress when receiving help from a foreign domestic helper.

Profile of Caregiver Needing Respite Care

Most caregivers were not aware of the term “respite care”, with nearly 6 in 10 not having heard about it. Participants understood respite care mostly in terms of temporary relief from caring for those in their charge (e.g. babysitting, child care, day care centre).

Finding #4

While hiring a foreign domestic worker might seem helpful, Helen constantly worries about her helper. There is perpetual uncertainty on whether she would stay on the job and be able to care effectively for 16-year-old Cedric, who has special needs. Holding a full-time job, she is especially concerned that her helper would leave on short notice, leaving her short-handed and with no immediate options to turn to.

“[My previous helper said] mum, I get another new employer, staying in a private house, condo, I’m sorry to tell you ah, that I would want to transfer there. And [even after] I paid for everything for her to come… After she (new helper) came in, I [started to] monitor her even when I’m in office. But she’s not keen at all to look after special needs children!”

Those who have encountered the term “respite care” found out about it through social service providers

Others came to know of it through the media or personal contacts

* Contrasts with the Singapore Survey on Informal Caregiving (Chan, Ostbye, Malhotra & Hu, 2013), which observed that caregivers of elderly care recipients experienced less stress when receiving help from a foreign domestic helper.
Caregivers regarded child safety, affordability and having trained personnel as important in respite care services.

<table>
<thead>
<tr>
<th>Components of Respite Care Services</th>
<th>% of Caregivers Who Rated as Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Safety</td>
<td>68%</td>
</tr>
<tr>
<td>Affordability</td>
<td>64%</td>
</tr>
<tr>
<td>Trained Personnel</td>
<td>55%</td>
</tr>
<tr>
<td>Convenience/Proximity</td>
<td>33%</td>
</tr>
<tr>
<td>Home Security</td>
<td>32%</td>
</tr>
<tr>
<td>Easy Access to Public Transport</td>
<td>26%</td>
</tr>
<tr>
<td>Feature Support Services for Caregivers</td>
<td>24%</td>
</tr>
</tbody>
</table>

Caregivers were more in favour of centre-based respite (e.g. day care centres, residential homes) of caregiving as opposed to informal or home-based care.

Caregivers expressed greatest need for respite care during situations of emergency.

In general, respite care was perceived as temporary and reactive, rather than constant and preventive.
STUDY ON PUBLIC ATTITUDES TOWARDS PERSONS WITH DISABILITIES

INTRODUCTION

Individuals live and relate to others, and are in turn influenced by them. Invariably, the society that a person exists in exercises a profound impact on the way that person behaves, thinks and feels – whether towards him or herself, and others. A society that looks upon a person differently for his or her disability has significant bearing on the affected individual’s quality of life. In the face of a dominant narrative that associates disability with challenge, persons with disabilities face everything from casual insensitivities, reduced career opportunities and even cultural aversion. On the contrary, a community that is caring and inclusive towards persons with disabilities significantly improves their quality of life, as it provides resources necessary for their acceptance in society.

Recognising the importance of community and society in the disability support ecosystem, NCSS conducted a study on Singaporean Citizens and Permanent Residents aged 18 to 69 years old to uncover the societal attitudes towards persons with disabilities.

A multidimensional survey sought to understand what members of the public understood and knew about persons with disabilities. It also looked at the level of acceptance and exposure to persons with disabilities in general and revealed domain-specific perceptions in key areas such as social interaction, education and employment.

To better understand the survey findings, focus group discussions were carried out subsequently with persons across all types of disability, to shed further light on needs and perspectives identified in the survey. It also touched on topics such as how they felt the public perceived them, how they wished to be treated as well as barriers to inclusion.

RESEARCH OBJECTIVES

- To establish a baseline for the public’s perception of, and understanding towards, persons with disabilities
- To understand the perception of opportunities and discrimination towards persons with disabilities in the areas of education, employment, social interaction and access to services and facilities
- To examine relationships between respondents’ demographic characteristics and their attitudes towards persons with disabilities

STUDIES

EDUCATION LEVEL

<table>
<thead>
<tr>
<th>No formal education/Primary</th>
<th>Secondary/Institute of Technical Education</th>
<th>Junior College/Polytechnic</th>
<th>Degree/Postgraduate</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.4%</td>
<td>36.8%</td>
<td>21.6%</td>
<td>25.3%</td>
</tr>
</tbody>
</table>

AGE

- 18-34: 31.1%
- 35-49: 30.9%
- 50-69: 38%

ETHNICITY

- Chinese: 74.7%
- Malay: 12.4%
- Indian: 10.4%
- Others: 2.5%

METHOD

The study was conducted in three stages, comprising a quantitative survey as well as pre- and post-survey qualitative components.

PRE-SURVEY QUALITATIVE

Five focus group discussions and an in-depth discussion were conducted with persons across a range of disabilities. To seek the perspectives of caregivers, a focus group discussion was held with caregivers of persons with Autism Spectrum Disorder and Down syndrome as well.

The objectives of these discussions were to understand the pain points of persons with disabilities, how the public views them and to guide the formation of the quantitative survey.

QUANTITATIVE SURVEY

To find out what members of the public thought about persons with disabilities, a representative, randomised sample of 1,500 Singaporeans was obtained from the Department of Statistics. The final sample achieved was 1,400, of which half were surveyed on Autism Spectrum Disorder and sensory impairment, while the other half, on physical impairment and intellectual disability.

The survey was done face-to-face and self-administered. Beyond demographics such as age and ethnicity, a composite instrument was constructed based on questions from a variety of scales and pilot-tested for reliability and validity (n = 200).

30 Out of 1,500 contacts. Response Rate = 93.3%.
31 In cases where participants were illiterate, responses were assisted. The “next birthday” method
32 Randomised sampling was performed on the 53 geographical areas that are equally distributed across Singapore, following which quotas were set by the respective house types within each area. Only Singaporean Citizens and Permanent Residents aged 18 to 69 years old were sampled.
33 Out of 1,500 contacts. Response Rate = 93.3%.
34 In cases where participants were illiterate, responses were assisted. The “next birthday” method
35 Scales consulted:
- Instruments
  - Disability Social Distance Scale (DSDS)
  - Scale of Attitudes Toward Disabled Persons (SADP)
  - Issues in Disability Scale (IDCS)
  - Multidimensional Attitudinal Scale (MAS)

CONCLUSION

The study identified several significant findings about public attitudes towards persons with disabilities. The results underscore the need for continued efforts in raising awareness and promoting inclusivity. Further research is recommended to explore how attitudes evolve over time and with interventions aimed at building a more inclusive society. The insights from this study can inform strategies for NCSS and other organisations working in the disability sector to create positive social change.
Respondents were queried on their attitudes, perceptions of, exposure to and knowledge regarding persons with disabilities. In particular, attitude scores were measured along three dimensions: Affect, Behaviour and Cognition.  

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affective</td>
<td>How the individual feels towards persons with disabilities.</td>
<td>“I am comfortable with a person who is with Autism Spectrum Disorder to be my supervisor.”</td>
</tr>
<tr>
<td>Behavioural</td>
<td>How the individual acts towards persons with disabilities.</td>
<td>“If I were an employer, I would hire persons who are with physical impairment.”</td>
</tr>
<tr>
<td>Cognitive</td>
<td>How the individual thinks about the role of persons with disabilities.</td>
<td>“I think that companies can benefit from hiring persons with disabilities.”</td>
</tr>
</tbody>
</table>

As a basis for comparison, participants were also asked to respond on the above categories with regard to a control group of persons without disabilities. In addition, they were asked on the extent that they would be comfortable relating to a person with disability, as a measure of social distance (e.g. as speaking acquaintances, close friends or to keep them out of Singapore).

POST-SURVEY QUALITATIVE
To better understand the needs and perspectives of persons with disabilities, NCSS commissioned a series of focus group discussions and interviews among persons across all types of disability. These were conducted with the help of various social service organisations including Bizlink, MINDS, DPA and Cheshire Home. A total of 88 respondents participated in the dialogues, which helped provide a better understanding of barriers to the inclusion of persons with disabilities as well as potential solutions in specific domains such as employment.

In addition, the perspectives of 33 sponsors, partners and other stakeholders were sought in a half-day workshop.

Discussions with persons with disabilities revealed that they felt treated differently because of their disability, be it in terms of:

1. **Stereotypes, judgements and misconceptions**
   “…they think (I) cannot contribute to society…when they talk to me, they won’t talk directly to me but to my sister or parents…but I’m only physically challenged, not mentally challenged.”
   – Focus group participant with physical impairment

2. **Over-protectiveness and differential treatment**
   “…my mother wouldn’t let me do anything by myself, not even wash the dishes, just because I don’t have an arm.”
   – Focus group participant with physical impairment

3. **Pity, and having “support” imposed upon them**
   “They don’t see us as able bodied…sometimes the lecturer will pity…and will give good grades.”
   – Focus group participant with hearing impairment

A multi-faceted approach to attitude. The underlying theory sees the construct of attitude in terms of what we feel (Affect), how we behave (Behaviour) or how we think (Cognition). (Olson & Zanna, 1993).
Attitudes towards persons with disabilities were least favourable in the domain of employment. Deeper probing suggests that the public often perceives a person’s disability as inability to perform one’s job.

Across disability types, the public feels and behaves more positively towards persons with physical or sensory impairment than those with intellectual disability or Autism Spectrum Disorder. For example, people feel less comfortable sitting next to a person with Autism Spectrum Disorder on the bus compared to someone in a wheelchair. They would also tend not to offer assistance to someone who has an intellectual disability, as they would to someone who is deaf.

Despite being qualified, focus group participant Steven was turned down at a job interview upon disclosing his disability. Eventually, he obtained an IT support position. The 24-year-old hopes that employers can be more inclusive and open-minded towards persons with disabilities:

“…even person[s] with disabilities, we can contribute to your profit. I don’t want to be a burden to whatever company that chooses to employ me. They have already given me a chance. I hope that they [employers] can continue to have an open mind – we will only ask for what adjustment[s] we need, because we understand the implication[s].”
The public displays a larger degree of social distance towards persons with intellectual disability or Autism Spectrum Disorder than those with physical or sensory impairment. The closest relationship that they would be comfortable with them, is at the level of colleagues in the same office.

Finding #4

Attitudes towards persons with disabilities were better with higher frequency of contact.

Finding #5

Finding #6

18-year-old Aditya was diagnosed with mild to moderate Autism Spectrum Disorder (ASD). As his mother and caregiver, focus group participant Jaya regards dignity to be more important than sympathy and empathy, and feels that it is important for people to develop a holistic understanding of persons with ASD by growing up in the same environments from young:

“When you grow up with classmates, live with neighbours with autism… that’s the time where awareness builds up… you have to be with them, understand them, interact with them.”

PUBLIC ATTITUDES WERE MORE POSITIVE FOR RESPONDENTS WHO HAD:

- Higher income
- Higher education level
- Larger housing type
- Younger age
A person’s experiences and perception of quality of life are inextricably linked to his or her ecosystem - the people close to him or her, as well as the attitudes of the wider society.

Findings from focus group discussions however, suggested a tension between persons with disabilities and their ecosystem. While they sought to be active and included as productive members of society, they were often hindered by well-meaning but sometimes overprotective caregivers as well as society’s preconceived notions and stereotypes about their abilities.

Towards applying the findings in a more direct manner, ideas and innovations (in Singapore or from overseas) are presented that adopt a person-centred and ecosystem approach in improving the lives of persons with disabilities. Where relevant, findings from the respective studies are referenced:

- Quality Of Life Study On Persons With Disabilities
- Needs Assessment On Respite Care For Caregivers Of Persons With Disabilities
- Study On Public Attitudes Towards Persons With Disabilities

This section is not meant to be prescriptive, but to highlight both existing and innovative models to inspire more solutions that are ground-up and suited to the community’s needs.

More solutions may be found in the Enabling Masterplan 3 document.
**IDEA #1** Achieve social inclusion by promoting active and meaningful participation in society.

Embracing persons with disabilities goes beyond eliminating discrimination. It means having a voice that is listened to, the ability to be involved in social and community activities and opportunities to achieve one’s personal potential in life.

Examining several facets of social inclusion and participation provides a guiding framework for thinking about how best to engage others to these ends:

*Effective communication serves as an essential means for anyone, not just persons with disabilities, to participate in social activities and have a chance at being socially included. While various methods (e.g. assistive technologies) are available to help with language and barriers to conversation, an equally important aspect involves advocating for wider awareness and adherence to respectful interaction etiquette. In this regard, the Removing Barriers series of booklets includes one for persons with disabilities, and details important terminology tips and methods of interaction sensitive to each disability. As communication is a two-way process, it is equally essential for persons with disabilities to be equipped with confidence to participate in social interaction as well.*

Of equal importance to inclusion is mutual respect. In particular, this means valuing what persons with disabilities have to say, but also listening to what is spoken. Such should apply not only to interpersonal conversations, but in other situations or social spaces, and where calling others out may be necessary. It entails learning about, being aware of and avoiding stereotypes, misconceptions and judgements. Being respectful goes hand in hand with being courteous, when needed. It means being open to offering help when requested and refraining from overly patronising treatment.

Starting from young can be an important means of nurturing respect, awareness and an understanding of others – all elements towards social inclusion. In this respect:

- **The Satellite Partnerships** are planned and sustainable partnerships, focusing on providing purposeful and appropriate integration opportunities between special education (SPED) and mainstream school students. Examples of such opportunities include joint Co-Curricular Activities, recess, workshops and camps. For some SPED students who are cognitively able to access the mainstream curriculum leading to national examinations, they have the opportunity for academic integration with their mainstream peers for some common subjects, where suitable.

- **The Inclusive Playgrounds** around Singapore feature accessible facilities for all to play. NCSS piloted Children In Action in 2015, an initiative that encourages social service organisations serving children with special needs to plan inclusive play activities – providing opportunities and access for children with special needs to play outdoors alongside their peers without special needs.

- **Buddy’IN** pairs students with mild intellectual disability with peers from mainstream schools to spend time together, including working on a graduation project. It has been piloted with students from the Association for Persons with Special Needs (APSN) Delta Senior School and ITE College West.
In the presence of mutual respect, helping persons with disabilities contribute meaningfully and to the best of their potential is significant to improving quality of life.

Persons with disabilities want to be socially included not just as a matter of compromise and accommodation, but also in a more active manner, by taking efforts to remain connected to community, society and nation.

Efforts could be made to include persons with disabilities in activities such as sports, gatherings in the neighbourhood, volunteering, and grassroots activities, or keeping them aware of disability services nearby. Ideally, persons with disabilities should be part of planning, outreach and decision-making processes, such as becoming role models to spread the awareness of services to peers, organising or facilitating events.

Activities could also be modified to encourage participation of everyone in the neighbourhood or in an area of interest. This is especially important as people tend to develop positive attitudes towards persons with disabilities as they interact with them more.

The most significant barrier to the inclusion and acceptance of persons with disabilities is one of attitudes rather than physical barriers. Persons with disabilities feel that the public views them as having limited capabilities and contributions to society, whereas in reality they aspire to lead meaningful and fulfilling lives.

In the UK, the Skillnet Group is a social enterprise that supports persons with learning difficulties. It operates on a core ideology of co-production, which entails:

- Making decisions and designing services with and alongside service users, instead of having them as purely on the receiving end
- Seeing the person and not their “problem”
- Avoiding distinctions between “staff” and “service users”

The group believes that while co-production as a practice might seem inefficient, costs more money and takes more time at the beginning, it is a preventive measure that significantly reduces the need to change decisions later, promotes initiative sustainability as well as helps clients be invested in the services they use.

It runs co-produced social businesses that offer paid work to clients, training to individuals and organisations to support persons with learning difficulties, and advocacy campaigns.

For instance, The Pulse is a fully accessible venue for workshops, trainings and events. Discovery Catering teaches people with (and without) learning difficulties how to cook fair-trade vegetarian and vegan food, which can be booked for patrons of The Pulse. Eco Shed recycles wood and other waste materials to create eco-friendly products (e.g. garden equipment, bird boxes) that are sold to the public.

Moving forward, the clarion call is to encourage the public to have willing hearts and open minds to embrace persons with disabilities as persons first, beyond recipients of help alone. This entails enhancing one’s awareness, empathy and having a good appreciation of the challenges they face as well as their ability and passion to contribute their fair share to the community.

Alongside public education campaigns and events, more could be done in all sectors of society, be it inclusive education, employment practices and support, along with more balanced media portrayals that emphasise similarity rather than difference, and ability rather than disability.

Ultimately, for a population that has been labelled as “special”, “disadvantaged” or “different”, it is vital to put the person before the disability, seeing them first for their individuality, strengths and ability to contribute to society.
Empowerment involves the expansion of one’s assets and capabilities, so that one can access resources and participate actively to achieve goals or solve problems. In this manner, the effects of gainful employment go a long way in empowerment – instilling a sense of autonomy and independence, but also identity. Beyond providing a stable income, it contributes to our individual self-worth, and is in itself an act of meaningful participation in society.

More support could also be facilitated in terms of transition support to the workplace. For example, work environments may not always be inclusive. Focus group discussions revealed that persons with physical and sensory impairment face issues with accessibility, communication or simply getting around. While some areas might be intuitive, employers should consult their employees to find out what needs may have been overlooked. Discretionary arrangements such as medical appointments or visits by caregivers should also be taken into account.

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Beyond issues of physical accessibility, persons with disabilities require skills to manage interpersonal relations effectively, be it with co-workers, supervisors or their clients. Training programmes which aim to debunk myths and stereotypes, promote strengths-based approaches and impart effective communication strategies for employees with disability, should be more commonplace. Where necessary, management-level staff could also help in being cognizant of incidents of discrimination. As a whole, enacting good social skills in the office contributes towards effective communication in other social arenas.

Inclusive public spaces help enable persons with disabilities to be independent, by being able to move about more easily. It is the first step towards social access and in turn acceptance, as there is an increased chance of encountering and interacting with them outdoors. This means equipping areas such as the home, school, the workplace and other public spaces to be universally accessible. Instituting physical access allows more persons with disabilities to be seen and alleviates the anxiety of not being able to get around, whether because of the absence of a curb cut or Braille instructions in lifts.

Incubating ideas for persons with disabilities to start their own businesses and providing them with resources and relevant services can be an empowering and exciting option. For this to work, multiple stakeholders have to come together to set up the necessary infrastructure, identify funding sources and run training programmes on business knowledge—how to harness the entrepreneurial spirit of persons with disabilities.

In Canada, the Entrepreneurs with Disabilities Program offers related services such as training and development, mentoring, and information resources, delivered through a nation-wide grassroots organisation called the Community Futures Network of Canada.

“...Inaccessibility affects [one’s] decision and confidence of coming outside."
— Focus group participant with physical impairment

There was a job I really wanted, it paid well and was good for me. But then, the toilet was so narrow, I can’t even turn into the toilet with my wheelchair. I would have to go to the next building just to go to the toilet, and there’s no shelter! What if it rains?"
— Focus group participant with physical impairment

41 Or allowance.
42 In conversation with the philosopher Judith Butler, disability activist Sunaura Taylor credits an increase in the public presence of the disabled to the public environment’s increased accessibility (Taylor, 2009).
When thinking about what universal accessibility looks like, five categories of access are useful:

- Circulation systems
- Entering and exiting
- Wayfinding
- Obtaining products and services
- Public amenities

Making public spaces more accessible to persons with disabilities is not only beneficial to them but their caregivers as well. For example, having a quiet room in a mall, eatery or cinema can greatly help persons with Autism Spectrum Disorder, who may need a space to calm down. Providing mobility devices or assistive technologies for rent in malls can also save the trouble of caregivers or persons with disabilities having to transport these devices with them, which can be troublesome. If malls have a concierge service to help persons with disabilities rent what they need, it might also relieve caregivers from having to be by their side, enabling them to get around by themselves.

However, accessing spaces is more than a matter of necessity. Spaces are also where social and leisurely activities occur – be it shopping, studying, working or hanging out. Being able to access them seamlessly allows unobstructed chances to be out with friends and family. This is particularly evident when one examines accessibility issues at a deeper and more intricate level. During focus group discussions, a visually impaired respondent related her difficulties buying popcorn and finding ticketed seats when bringing her children to the cinema, while watching the news on television proved a struggle for a participant who had a hearing impairment.

Another helpful tool is to ask people what they need. In Japan, Fukuoka’s subway system has been lauded for its design which makes it highly accessible for persons with disabilities. Upon consultation with affected commuters, the stations were designed with many key features. Signs and ticket booths are positioned at a height that is at a lower level for the convenience of wheelchair users, while large, tactile signs with audible information are available for visually impaired persons.

The Viviana Mall in Thane, Mumbai uses audio-tactile technology to build a more inclusive environment for the visually-impaired. With either their fingers or ears, mall patrons can read shop names, peruse restaurant menus and get around using an audio-tactile floor plan. Similar adaptations could be made for the home, such as labelling medicine bottles or common utilities.

Finally, technology can also be mobilised to help persons with disabilities achieve greater independence, particularly in day-to-day tasks. To mitigate purchasing and maintenance costs, individuals should be able to tap on funds such as SG Enable’s Assistive Technology Fund.44

A ceiling hoist helps move individuals without the use of a wheelchair, reducing the risk of injury to caregivers or users as a result of lifting or dropping during such transfers. It also allows caregivers to employ time and effort saved on lifting on other tasks. It can be used for other purposes such as rehabilitation, and has a portable version for travel use.

Tinitell is a wearable mobile phone with calling and smart location functions. Although designed for children, its utilities can be extended to adults with disability as well. It also has other features such as reading the time out loud or customisable voice messages for each contact that calls the wearer.

IDEA #3 Support caregivers.

At some point in our lives, everyone either is or will need a caregiver. While our attention is often drawn to those in immediate need, it is worthwhile to consider the unsung heroes who care for them on a daily basis.

Caregivers should be recognised as having needs to be met, just like everyone else. Accepting this is critical for deeper conversations on how these needs can be met, directs attention to caregivers and encourages caregivers themselves to call for help when needed. Furthermore, it requires the understanding that one’s quality of care is often contingent on one’s own quality of life.

In supporting social care professionals to facilitate conversations around caregiving, the NCSS Pumpkin Lab has co-created a set of tools with stakeholders from the social sector. The We Care Toolkit is part of a journal which aims to help professionals explore the experiences of caregivers. Some tools help to open up a conversation whilst others help to frame caregiving differently.

The journal was part of a larger design study which delved into the experiences of caregivers with complex needs in Singapore. Details of the study as well as other innovative solutions on how to support caregivers can be found in the Who Cares? publication.

All materials and more information can be found at www.ncss.gov.sg/caregiving.

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In particular, feedback was given that existing efforts to help new caregivers of children of special needs were not concerted. Thus, it is recommended that a more standardised procedure and support structure be put in place for caregivers who have children newly diagnosed with special needs.

Finally, it is important to bring caregivers to a greater awareness of what “respite care” means. Most caregivers have never heard of the term. Those who have, regard it as a reactive measure in times of urgency rather than the possibility that respite care may be an area of need on a more regular basis. Thus, the importance of caregivers proactively seeking help should be made known — ideally through public education efforts that highlight the positive, though less apparent, effects of constant respite, including:

- Timely support
- Earlier and steadier awareness of caregivers’ needs
- Prevention of caregiver burnout, which not only affects the caregiver but also care recipients and family
- A listening ear to caregivers, whose journey can be a lonely and challenging one

Improving awareness on home-based respite care options, as well as its benefits, widens the array of services for caregivers and allows help to be delivered in one’s home.

Jaga-Me is an on-demand home care app that connects users to experienced nursing care professionals, medical escorts, trained caregivers or care managers who can deliver home care in a variety of ways. All nurses are locals and licensed by the Singapore Nursing Board, and have a minimum of two years of professional experience in a hospital.

In April 2016, SingHealth piloted its Match-A-Nurse programme, enabling institutional nurses to formally provide home nursing services to home-bound patients living nearby. It matches nurses to service users based on proximity.

44 Depending on household income, it subsidises up to 90% of the cost of assistive technology devices for persons certified to have a permanent disability, subject to a lifetime cap of $40,000.
### THE DISABILITY SERVICE LANDSCAPE

The major social services which cater to persons with disabilities and their caregivers are tabled below. For more information, a glossary is attached in Annex B.

46 Services tabled are not exhaustive.

* Indicates programmes in the pilot phase.

#### PERSONS WITH DISABILITIES

<table>
<thead>
<tr>
<th>Mild</th>
<th>Severe</th>
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</thead>
<tbody>
<tr>
<td><strong>CHILDOOD</strong> <em>(0-6 YEARS)</em></td>
<td><strong>YOUTH</strong> <em>(7-18 YEARS)</em></td>
</tr>
<tr>
<td>Learning Support-Development Support</td>
<td><strong>MAINSTREAM EDUCATION</strong></td>
</tr>
<tr>
<td>Integrated Child Care Programme</td>
<td>Integration Support</td>
</tr>
<tr>
<td>Early Intervention Programme for Infants and Children</td>
<td>I. M. Powered*</td>
</tr>
<tr>
<td></td>
<td>Learning Support</td>
</tr>
<tr>
<td><strong>SPECIAL EDUCATION</strong></td>
<td>Drop-in Disability Programme</td>
</tr>
<tr>
<td>Special Education Schools</td>
<td>Community Group Homes</td>
</tr>
<tr>
<td>Special Student Care Centres</td>
<td>Adult Disability Hostels</td>
</tr>
<tr>
<td>Buddy’IN*</td>
<td>Me Too! Club*</td>
</tr>
<tr>
<td>Children Disability Homes</td>
<td>Adult Disability Homes</td>
</tr>
<tr>
<td>Inclusive Playgrounds &amp; Children-in-Action*</td>
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</tbody>
</table>

#### CAREGIVERS

<table>
<thead>
<tr>
<th>RESPIE CARE</th>
<th>TRAINING</th>
<th>PSYCHOSOCIAL</th>
<th>FINANCIAL-RELATED</th>
<th>INFORMATION AND REFERRAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Disability Homes/Hostels (short-term, from days to weeks)</td>
<td>Psychosocial and Family Dynamics (e.g. AWWA)</td>
<td>Support Groups (e.g. Centre-Based, Groups formed organically by Caregivers)</td>
<td>General (e.g. ComCare, Ray of Hope)</td>
<td>SG Enable (for all Disability-related matters and services)</td>
</tr>
<tr>
<td>Drop-in Disability Programme (short-term, for a few hours)</td>
<td>Technical Skills Training (e.g. Autism Resource Centre)</td>
<td>Counselling (e.g. MDAS, AWWA)</td>
<td>Disability-Specific (e.g. Club Rainbow, SPD Education Programme)</td>
<td></td>
</tr>
<tr>
<td>Disability Social Service Organisations/Agencies</td>
<td></td>
<td>Parent-Mentor programmes (e.g. DSA, MDAS)</td>
<td>Assistive Technology (e.g. Assistive Technology Fund)</td>
<td></td>
</tr>
<tr>
<td>Disability Social Service Organisations/Agencies</td>
<td></td>
<td></td>
<td>Transport (e.g. Caring Fleet Services Limited, TransportAid)</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Special Needs Trust Company</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Caregivers Training Grant</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Foreign Domestic Worker Grant/Levy Concession</td>
<td></td>
</tr>
</tbody>
</table>

* Indicates programmes in the pilot phase.

**Annex B**
WHAT CAN YOU DO?

At the end of the day, everyone plays an important role in the disability support ecosystem. Here are some suggestions for what you can do:

<table>
<thead>
<tr>
<th>IF YOU ARE A...</th>
<th>YOU CAN...</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERSON WITH DISABILITY</td>
<td>Speak up, live life to the fullest, volunteer and participate in society. If you need help, visit SG Enable’s website (<a href="http://www.sgenable.sg">www.sgenable.sg</a>) – a one-stop site connecting you to programmes and schemes available, including a disability employment portal.</td>
</tr>
<tr>
<td>EMPLOYER</td>
<td>Consider applying for benefits under the Special Employment Credit scheme, where the government pays a proportion of the wages of employees with disabilities. Seek out grants and initiatives such as the Open Door Fund, to find out more about support for hiring persons with disabilities in your organisation. Head over to SG Enable’s Disability Employment Portal (employment.sgenable.sg) and explore the host of schemes and training programmes available. Help make the workplace more inclusive. Give persons with disabilities a chance, and ascertain their strengths instead of deciding their weaknesses.</td>
</tr>
<tr>
<td>SERVICE PROVIDER</td>
<td>Innovate. This need not be about the next big thing, but doing a little differently with what’s around you. For example, taking always helps – network and collaborate with others in the field. Co-create services with your clients, give them a voice and empower them to make decisions on what they want – allowing them to take ownership of what they themselves are part of.</td>
</tr>
<tr>
<td>GRASSROOTS WORKERS</td>
<td>Design community activities that are inclusive towards persons of all disabilities, be it activities that also allow caregivers to participate, hiring an interpreter or having contingency plans in cases of emergencies. Reach out to those in the neighbourhood with a disability, and ask what they need help with.</td>
</tr>
<tr>
<td>CO-WORKER/ FRIEND</td>
<td>Avoid making assumptions about your co-worker, acquaintance or friend with disability. When in doubt, ask – be it their preferences or what they are comfortable with doing. Start a conversation with them, instead of about them, and talk about things openly.</td>
</tr>
<tr>
<td>CAREGIVER/ FAMILY</td>
<td>Don’t be afraid to confide in others. If you need help, reach out to friends, family or other service providers. Find out about the different programmes available for children and adults with disabilities on SG Enable’s website, which can alleviate some of your caregiving responsibilities.</td>
</tr>
<tr>
<td>MEMBER OF THE PUBLIC</td>
<td>Ask before you help, and if you are approached for it, listen to what the person with disability needs help with. Don’t feel offended or embarrassed if your help is declined. Speak directly to him or her, not to his companion, and be sensitive about physical contact. Also, persons with disabilities can sense pity and hesitation, which makes them more aware of their differences and reluctant to ask for help in the future – even when they need it. Download a copy of the Removing Barriers series of NCSS’ website and share it with people you know. It helps others understand the challenges that persons with disabilities face, and encourage inclusive behaviour. To donate or volunteer for a disability-related cause, head over to Giving.sg’s website (<a href="http://www.giving.sg">www.giving.sg</a>) to care deeply and share freely.</td>
</tr>
</tbody>
</table>

A list of hotlines may be found on the back cover.

ACKNOWLEDGEMENTS

We would like to thank all our respondents, who have been gracious and kind enough to share their opinions, thoughts and stories, so that many may benefit. Special thanks also to our consultants, social service providers and partners, for providing us with your support, feedback and assistance.

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- Anjan Ghosh

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**Needs Assessment on Respite Care for Caregivers of Persons with Disabilities**

- Dilsy Tan
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- Benjamin Tay

**Study on Public Attitudes Towards Persons with Disabilities**

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- In memory of: Prof Michael Power (1954-2017)
- National University of Singapore

**Needs Assessment on Respite Care for Caregivers of Persons with Disabilities**

- A/Prof Marcus Chiu
- City University of Hong Kong

**Study on Public Attitudes Towards Persons with Disabilities**

- Mr Wan Kum Seong, A*STAR

**SOCIAL SERVICE PROVIDERS**

**APSN – Chaoyang School**
- AWWA Centre for Caregivers

**AWWA School**
- AWWA Special Student Care Centre
- Bizlink Centre
- Blue Cross Thong Kheng Home Day Activity Centre
- CPAS Day Activity Centre
- CPAS Goodwill, Rehabilitation and Occupational Workshop
- CPAS School
- Christian Outreach for the Handicapped Emmanuel Activity Centre @ Toa Payoh
- Down Syndrome Association
- Eden Children’s Centre (Simei)
- Grace Orchard School
- Handicapped Welfare Association
- Lighthouse School
- Metta PreSchool @ Punggol
- Metta School

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- Ministry of Social and Family Development
- SG Enable
- and all who have contributed to the research and this publication in one way or another.

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- MINDS Ang Mo Kio Training & Development Centre
- MINDS Clementi Training & Development Centre
- MINDS Towner Gardens School
- Muscular Dystrophy Association Singapore
- Rainbow Centre Yishun Park School
- Singapore Association for the Deaf
- Singapore Association for the Visually Handicapped
- SPD Jurong
- Special Needs Trust Company
- St. Andrew’s Autism School
- The Disabled People’s Association
- The Singapore Cheshire Home
- Thye Hua Kwan Moral Charities
- Early Intervention Programme for Infants and Children Centre @ Tampines
- TOUCH Centre for Independent Living
- TOUCH Club

- MINDS Towner Gardens School
- AWWA School
- AWWA Special Student Care Centre
- Bizlink Centre
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ANNEX A: GLOSSARY OF QUALITY OF LIFE DOMAINS AND FACETS

<table>
<thead>
<tr>
<th>DOMAIN</th>
<th>FACET</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>Pain and Discomfort</td>
<td>This facet explores unpleasant physical sensations experienced by a person and the extent to which these sensations are distressing and interfere with life.</td>
</tr>
<tr>
<td>Environmental Quality</td>
<td>Energy and Fatigue</td>
<td>This facet explores the energy, enthusiasm and endurance that a person has in order to perform the necessary tasks of daily living, as well as other chosen activities such as recreation.</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>Sleep and Rest</td>
<td>This facet concerns how much sleep and rest, and problems in this area, affect the person's quality of life.</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>Level of Independence</td>
<td>This facet examines the person's view of his or her ability to get from one place to another, to move around the home, move around the work place, or to and from transportation services.</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>Activities of Daily Living</td>
<td>This facet explores a person's ability to perform usual daily activities.</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>Dependence on Medication or Treatments</td>
<td>This facet examines a person's dependence on medication or alternative medicines for supporting his or her physical and psychological well-being.</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>Work Capacity</td>
<td>This facet examines a person's use of his or her energy for work. “Work” is defined as any major activity in which the person is engaged.</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>Personal Relationships</td>
<td>This facet examines the extent to which people feel the companionship, love and support they desire from the intimate relationship(s) in their life. It also addresses commitment to and current experience of caring for and providing for other people.</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>Social Support</td>
<td>This facet examines how much a person feels the commitment, approval, and availability of practical assistance from family and friends.</td>
</tr>
<tr>
<td>Social Relationships</td>
<td>Sexual Activity</td>
<td>This facet concerns a person's urge and desire for sex, and the extent to which the person is able to express and enjoy his or her sexual desire appropriately.</td>
</tr>
<tr>
<td>Environment</td>
<td>Opportunities to Acquire New Information and Skills</td>
<td>This facet examines a person's opportunities and desire to learn new skills, acquire new knowledge and feel in touch with what is going on.</td>
</tr>
<tr>
<td>Environment</td>
<td>Recreation and Leisure</td>
<td>This facet explores a person's ability, opportunities and inclination to participate in leisure, pastimes and relaxation.</td>
</tr>
<tr>
<td>Physical Environment</td>
<td>Safety and Security</td>
<td>This facet examines the person's sense of safety and security from physical harm.</td>
</tr>
<tr>
<td>Physical Environment</td>
<td>Home Environment</td>
<td>This facet examines the principal place where a person lives, and the way that this impacts on the person's life.</td>
</tr>
<tr>
<td>Financial Adequacy</td>
<td>Financial Adequacy</td>
<td>This facet explores the person's view of how his or her financial resources and the extent to which these resources meet the needs for a healthy and comfortable lifestyle.</td>
</tr>
<tr>
<td>Health and Social Care</td>
<td>Health and Social Care</td>
<td>This facet examines the person's view of how his or her health and social care needs are being met.</td>
</tr>
</tbody>
</table>

**REFERENCES**


## TERM DESCRIPTION

### Children-in-Action* A programme that offers outdoor social activities and free play for children with and without special needs at the various Inclusive Playgrounds. It is organised by various social service organisations, who plan and implement the activities.

### Community Group Home An alternative housing option for persons with disabilities to live independently with the community, in designated rental flats retrofitted with disability-friendly features.

### Day Activity Centre Provides day programmes for individuals aged 16 to 35 years and with moderate to low functioning ability. It aims to enhance their independence by equipping them with daily and community living skills, or skills to transit to workshop employment.

### Developmental Disability Registry A registry for persons with developmental disabilities and persons with dementia, it offers an Identity Card which lists contact and other information that helps members of the public identify and extend appropriate assistance to cardholders.

### Drop-In Disability Programme Provides social, recreational, training and therapeutic activities for adults with disabilities who are sufficiently independent, for a few hours each week in a community-based centre.

### Early Intervention Programme for Infants and Children Provides therapy and educational support services for infants and young children with special needs, to maximise their developmental growth potential and minimise the development of secondary disabilities. It seeks to equip them with improved motor, communication, social, self-help and cognitive skills.

### Emergency SMS Helpline Service Provides persons with hearing loss or speech difficulties with an avenue for communication to the Police or the Singapore Civil Defence Force in times of emergency, such as life-threatening situations or serious injury.

### Family Service Centre Centres based in the community which provide help and support to individuals and families in need, supporting them to better cope with personal, social and emotional challenges.

### Foreign Domestic Worker Grant/LTV Concession The Grant is a $120 monthly cash payment given to families who need to hire a Foreign Domestic Worker to care for persons who require permanent assistance in at least three Activities of Daily Living (i.e. eating, bathing, dressing, transferring, toileting, walking or moving around).

### Home-Based Care Services Provides alternative care support for adults with disabilities, with the aim of keeping them in the community for as long as possible. Services include therapy, personal hygiene care, housekeeping and medication reminders.

### I. M. Powered* An upstream intervention to enhance the mental well-being of children and youth with disabilities in mainstream schools. It equips them and their parents with the knowledge and skills to strengthen resilience in coping with challenges.

### Inclusive Playground A playground for children with and without special needs to play together, it offers various features including a wheelchair-accessible swing and merry-go-round, an adventure tube that provides a corner for children who need a break from stimulations and interactive panels that simulate auditory and touch senses.

### Integrated Child Care Programme An inclusive child care programme for children aged 2 to 6 years old with mild special needs. It provides a natural environment for them to learn, play and socialise alongside mainstream peers, preparing them for future entry into mainstream primary education.

### Buddy’IN A programme aimed at socially integrating graduating students from Special Education schools with Technology

### Appropriate Adults Service Provides assistance to persons with intellectual or mental disability (PWIDs) who are required to give a statement to the Police during investigations.

### Asistive Technology Technologies that aid persons with disabilities in the areas of communications, early intervention, education, employment, independence in daily living, rehabilitation, security, therapy and training.

### Buddy’IN* A programme aimed at socially integrating graduating students from Special Education schools with Technology

### Caregivers Training Grant A $200 annual subsidy (per care recipient) that lets caregivers attend approved courses to better care for loved ones.

### Children Disability Home Provides long-term residential care to children with disabilities who are neglected or whose caregivers are incapable of caring for them. Some homes also provide short-term respite care for those whose families are unable to provide care temporarily.

### Concession Worker Grant/Levy The Levy Concession lets families pay a monthly foreign domestic worker levy of just $60, instead of $265. Each household gets concessions for up to two foreign domestic workers for two loved ones. Care recipients must be between 16 and 64 years of age and have trouble with at least one of the Activities of Daily Living.

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### Psychological Positive Feelings This facet examines how much a person experiences positive feelings of contentment, balance, peace, happiness, hopefulness, joy and enjoyment of the good things in life.

### Thinking, Learning, Memory and Concentration This facet explores a person's view of his or her thinking, learning, memory, concentration and ability to make decisions. This incorporates the speed of thinking and clarity of thought.

### Self-Esteem This facet examines how people feel about themselves. This might range from feeling positive about themselves to feeling extremely negative about themselves.

### Body Image and Appearance This facet examines the person's view of his or her body. Whether the appearance of the body is seen in a positive or negative way is included in this facet.

### Negative Feelings This facet concerns how much a person experiences negative feelings, including despondency, guilt, sadness, tearfulness, despair, nervousness, anxiety and a lack of pleasure in life.

### Personal Beliefs Personal Beliefs, Spirituality/Religion This facet examines the person's personal beliefs and how these affect quality of life. This might be by helping the person cope with difficulties in his/her life, giving structure to experience, ascribing meaning to personal questions and providing the person with a sense of well-being.
**Integration Support**
A variety of programmes which aim to support persons with disabilities in daily life, and integrate them into mainstream activities and the community.

The support received may include therapeutic, recreational or social elements. Examples of such organisations include Riding for the Disabled Association Singapore (riding therapy), MINDS (Community Model in the Day Activity Centre), and AWWA (Community Integration Services).

**Job Placement & Job Support**
Promotes the employment and retention of persons with disabilities in the workforce. Job-ready persons with disabilities will be supported for job placement and job support through SG Enable’s appointed partners (e.g. Autism Resource Centre, SPD and Movement for the Intellectually Disabled Singapore).

**Learning Support**
Specialised learning support services for mainstream students under 13 who have been diagnosed or assessed to have learning difficulties. These services aim to develop their literacy skills and self-confidence, and help parents in supporting their children.

**Learning Support- Development Support**
Provides targeted developmental and learning support in preschools of children with mild moderate developmental needs, to improve children’s developmental outcomes and achieve better school readiness.

**Me Too! Club**
A semi-structured programme that aims to reduce social isolation and enhance the integration of adults with moderate to severe disabilities who are not accessing services. It engages them through regular social activities, outings and befriending services.

**Rehabilitation and Therapy Services**
Help adults with disabilities overcome challenges they may face in development, mobility and socialising with others. Services include physiotherapy, occupational therapy and speech therapy.

**SG Enable**
A one-stop agency dedicated to serving and enabling persons with disabilities.

**Sheltered Workshop**
Offers employment and/or vocational training to adults with disabilities who do not possess the competencies or skills for open employment. Participants practise in jobs or tasks where the processes are either simple or broken down into simpler steps, allowing them to gain valuable experience and improve their prospects for open employment.

**Social Service Office**
Brings social assistance closer to residents in the community who are in need, making ComCare and other forms of assistance such as job-matching and family services more accessible.

**Special Education (SPED) School**
Offers customised curricula and educational programmes aimed at developing the potential of students, helping them to be independent, self-supporting and contributing members of society. There are 20 schools in total, which run different programmes that cater to various disability groups of students. Besides being taught by their teachers, students in all SPED schools also receive support from allied health professionals such as psychologists, speech therapists, occupational therapists, physiotherapists and social workers.

**Special Needs Trust Company**
Provides trust services and set-up and management of an endowment fund for the benefit of persons with special needs.

**Social Service Office**
Brings social assistance closer to residents in the community who are in need, making ComCare and other forms of assistance such as job-matching and family services more accessible.

**Special Needs Trust Company**
Provides trust services and set-up and management of an endowment fund for the benefit of persons with special needs.

**Special Student Care Centre**
Provides before/after-school care services for students aged 7 to 18 years old with special needs, and who attend mainstream or SPED schools. **Integrated Student Care Centres** are mainstream student care centres catering to both mainstream students and students with mild to moderate social needs, while **Dedicated Student Care Centres** are located in SPED schools and cater only to students with special needs.

**Vocational Training/ Education**
Aims to provide accessible and targeted training and upskilling for persons with disabilities to be job-ready and stay relevant at the workplace. The **Enabling Academy**, for example, facilitates the development of curricula and customised programmes, and works alongside training providers to train employees with disabilities whenever possible.

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* indicates programmes in the pilot phase.

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**Hotlines**

<table>
<thead>
<tr>
<th>Service</th>
<th>Hotline</th>
</tr>
</thead>
<tbody>
<tr>
<td>SG Enable</td>
<td>1800 858 5885</td>
</tr>
<tr>
<td>MINDS Caregiver Support Services</td>
<td>6547 8503</td>
</tr>
<tr>
<td>Special Needs Trust Company</td>
<td>6278 9598</td>
</tr>
</tbody>
</table>

Individuals are part of, influence and are influenced by a larger system comprising other players such as caregivers, government and society at large.

Guided by these principles, NCSS conducted a series of studies to understand those in need, towards helping individuals achieve quality of life.

Person-Centred
 Individuals are core, diverse and essential set of needs, regardless of disability, cultural or socio-economic status.

Quality of Life
 Individuals possess a core, diverse and essential set of needs, regardless of disability, cultural or socio-economic status.

Ecosystem
 Individuals are part of, influence and are influenced by a larger system comprising other players such as caregivers, government and society at large.

NCSS takes a person-centred and ecosystem approach to understanding those in need, towards helping individuals achieve quality of life.

QUALITY OF LIFE STUDY ON PERSONS WITH DISABILITIES

STUDY ON PUBLIC ATTITUDES TOWARDS PERSONS WITH DISABILITIES

Taking the World Health Organisation’s Quality of Life Framework, the Quality of Life Study on Persons with Disabilities sought to understand the needs of individuals with physical, sensory and intellectual impairments through a bio-psycho-social-spiritual lens.

QUALITY OF STUDY ON PERSONS WITH DISABILITIES

NEEDS ASSESSMENT ON RESpite CARE FOR CAREGivers OF PERSONS WITH DISABILITIES

Nearly half of caregivers of persons with disabilities experienced caregiver strain, with a larger frequency of psychological distress. Many feel burdened by the weight of caregiving.

Factors Contributing to Caregiver Stress:
• Disability of care recipient is severe
• Care recipient is young
• Chronic illness in caregiver or care recipient
• Care recipient has an intellectual disability or Autism Spectrum Disorder
• Low average household income
• Caregiver is highly educated

Profile of Caregiver Needing Respite Care:
• Has a chronic illness
• Higher income or education
• Employs a foreign domestic worker

Caregivers expressed the greatest need for respite care during emergencies. They perceived respite care as a temporary and reactive measure as opposed to a preventive one.

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Caregivers expressed the greatest need for respite care during emergencies. They perceived respite care as a temporary and reactive measure as opposed to a preventive one.
Develop more effective communication, towards mutual understanding.
• Encourage respectful interaction etiquette such as in the Removing Barriers series
• Give persons with disabilities the confidence to step out of their comfort zones

Encourage and inculcate respect.
• Value what persons with disabilities have to say
• Be aware of and avoid stereotypes, misconceptions and judgements, calling others out where necessary
• Offer help when requested, but refrain from overly patronising treatment
• Promote opportunities for social integration between children and with and without disabilities, such as the Satellite Partnership between mainstream and special education (SPED) schools, Inclusive Playgrounds and Buddy’IN

Achieve social inclusion by promoting active and meaningful participation in society.

Help persons with disabilities to contribute meaningfully to society, and to the best of their potential.
• Be inclusive in both intention and design, whether it be grassroots activities, neighbourhood gatherings or volunteer opportunities
• For example, the Skillnet Group in the UK co-creates innovative social businesses with persons with learning difficulties

Change public attitudes and encourage them to embrace persons with disabilities as persons first.

Help public spaces be more inclusive.
• Have disability support measures such as a quiet room, mobility devices for rent, large signs or audible information
• Ensure universal access inside public spaces, beyond access to them
• For example, Viviana Mall in Mumbai uses audio-tactile technology for shop names, restaurant menus and even floor plans

Appropriate technologies that enable independence, such as:
• A ceiling hoist that helps individuals move about more independently
• Tinitell, a wearable mobile phone that can read callers’ names and the time out loud

Empower towards independence through greater and accessible opportunities.

Help persons with disabilities in their transition to the workplace.
• Ensure that work environments are inclusive in terms of accessibility, communication and accommodations that help them to be independent
• Help persons with disabilities manage interpersonal relations effectively through social skills training
• Provide social skills programmes to colleagues that debunk myths and stereotypes about disability, promote strengths-based approaches and impart effective communication strategies
• Be sensitive to incidents of discrimination

Support caregivers.

Focus on the needs of caregivers beyond their care recipients.
• Recognise that caregivers’ quality of care is dependent on their own quality of life
• Use the We Care Toolkit to derive deep insights from caregivers’ experiences, opening up vital conversations and reframing caregiving in a different light

Equip hospitals to be key touch points for caregivers.
• Have standardised protocols and structures for caregivers, especially for those with children newly diagnosed with special needs

Focus caregiver support on psychological support, training and self-care, such as counselling services, courses and support or resource networks.

Provide or improve access to temporary respite care options that cater to emergency situations.

Boost caregivers’ awareness of respite care, such as through public education.
• Encourage them to seek help proactively
• Highlight the positive effects of caregiver-centred respite, such as the prevention of caregiver burnout, and more timely support
• Improve knowledge and attractiveness of home-based respite care through innovation in options like Jaga-Me or Match-A-Nurse that match professional nurses to home users

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