

UNDERSTANDING

THE **QUALITY OF LIFE** OF

**ADULTS WITH  
DISABILITIES**

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DISABILITIES

*This publication is also available online at <https://www.ncss.gov.sg/Press-Room/Publications>*

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## PRESIDENT'S FOREWORD

**MR HSIEH FU HUA**  
NCSS President

*"That food goes uneaten and families remain vulnerable tells us that hunger is but one need among many."*

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.



## FOREWORD

**DR GERARD EE**  
Chairman of the NCSS Advocacy and Research Panel

*"Regardless of ability, condition or age, our lives are made up of many diverse facets, aspects and experiences intricately woven together."*

Regardless of ability, condition or age, our lives are made up of many diverse facets, aspects and experiences intricately woven together. Even as individuals, we are shaped by the ecosystem we live in, be it the people close to us, community or wider society. Hence, focusing on a few aspects rather than the whole – the individual rather than his or her interactions with the entire ecosystem – prevents us from seeing meaningful linkages that contribute to who a person is.

With this in mind, NCSS carried out a series of studies to examine the quality of life of various vulnerable populations and seniors through a person-centred and holistic approach. To understand their aspirations, needs and well-being from their perspective, we adopted the World Health Organisation's framework on Quality of Life, conducting surveys, interviews and discussions.

This is one in a series of publications that presents the results of those findings to practitioners, social service professionals, volunteers and service users for their application. Each contains rich information that can be used to guide social service providers, funders and other stakeholders in the social service ecosystem, to dive into understanding and developing solutions so as to empower service users towards achieving their fullest potential.

Among numerous applications, the insights gleaned from these findings have contributed towards national initiatives such as the Enabling Masterplan 3, the nation's disability blueprint, as well as the Social Service Sector Strategic Thrusts, a five-year strategic roadmap for the sector developed in partnership with the public, private and people sectors.

I am extremely grateful to our advisors. They are experts in the field of statistics, psychology, social work, disability, mental health and seniors and research. I am also thankful to each and every respondent who participated in the study, along with the many who helped ensure that their opinions were heard.



Photo credit: The Human Library

## MESSAGE

**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."*

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 schoolmates' 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.

## AN OVERVIEW OF DISABILITY



<sup>1</sup> World Health Organization. (n.d.). *Disabilities*. This definition reflects a bio-psycho-social model of disability.

**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**

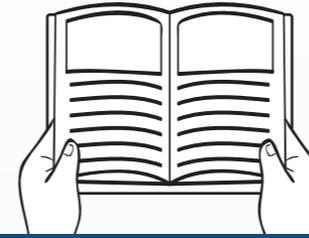
A birth defect of the spine that manifests in various forms of severity. **Spina bifida occulta** is the mildest form, having no signs and symptoms or neurological problems. More severe manifestations include **meningocele** or the potentially life-threatening **myelomeningocele** (open spina bifida).

**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.



**LEARNING**

Cognitive deficits that impact academic achievement.

**DYSCALCULIA**

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

**DYSPRAXIA**

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

**DYSLEXIA**

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

**DYSGRAPHIA**

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



**DEVELOPMENTAL**

Diverse group of conditions that occur in the developmental period of a child, resulting in difficulties in personal, social, academic or occupational functioning<sup>2</sup>.

**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).

<sup>2</sup> American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders: DSM- 5*.



**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**

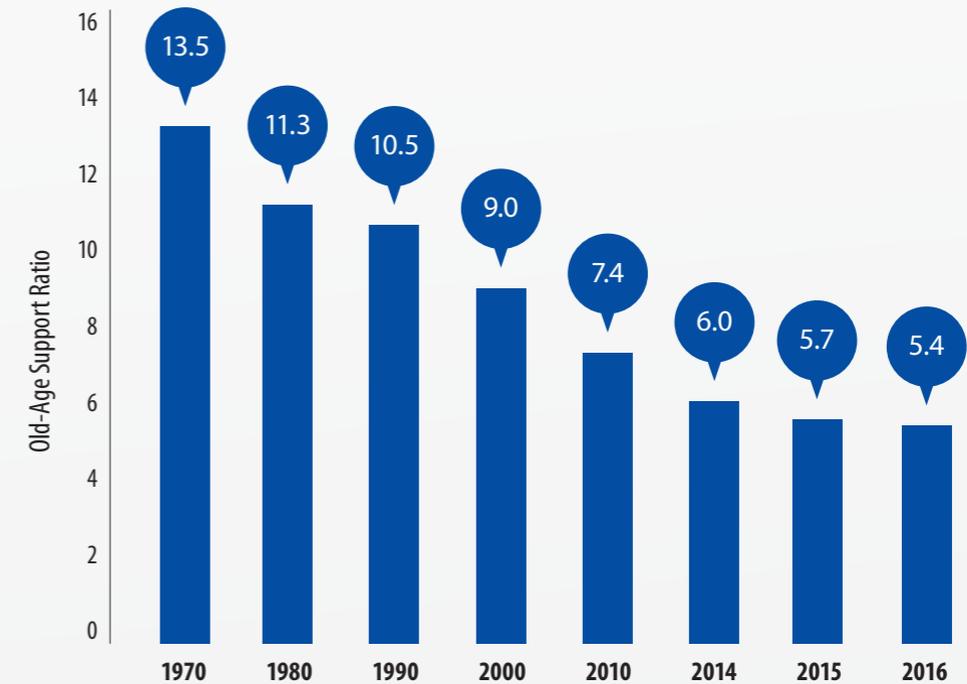
**POST-18**

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

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.

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, NCCSS 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.<sup>3</sup>

## 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.<sup>4</sup>

## ECOSYSTEM

Addressing individuals holistically also means seeing them as enmeshed in different, interrelated contexts that influence every aspect of an individual's life - an *ecosystem*<sup>5</sup> 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

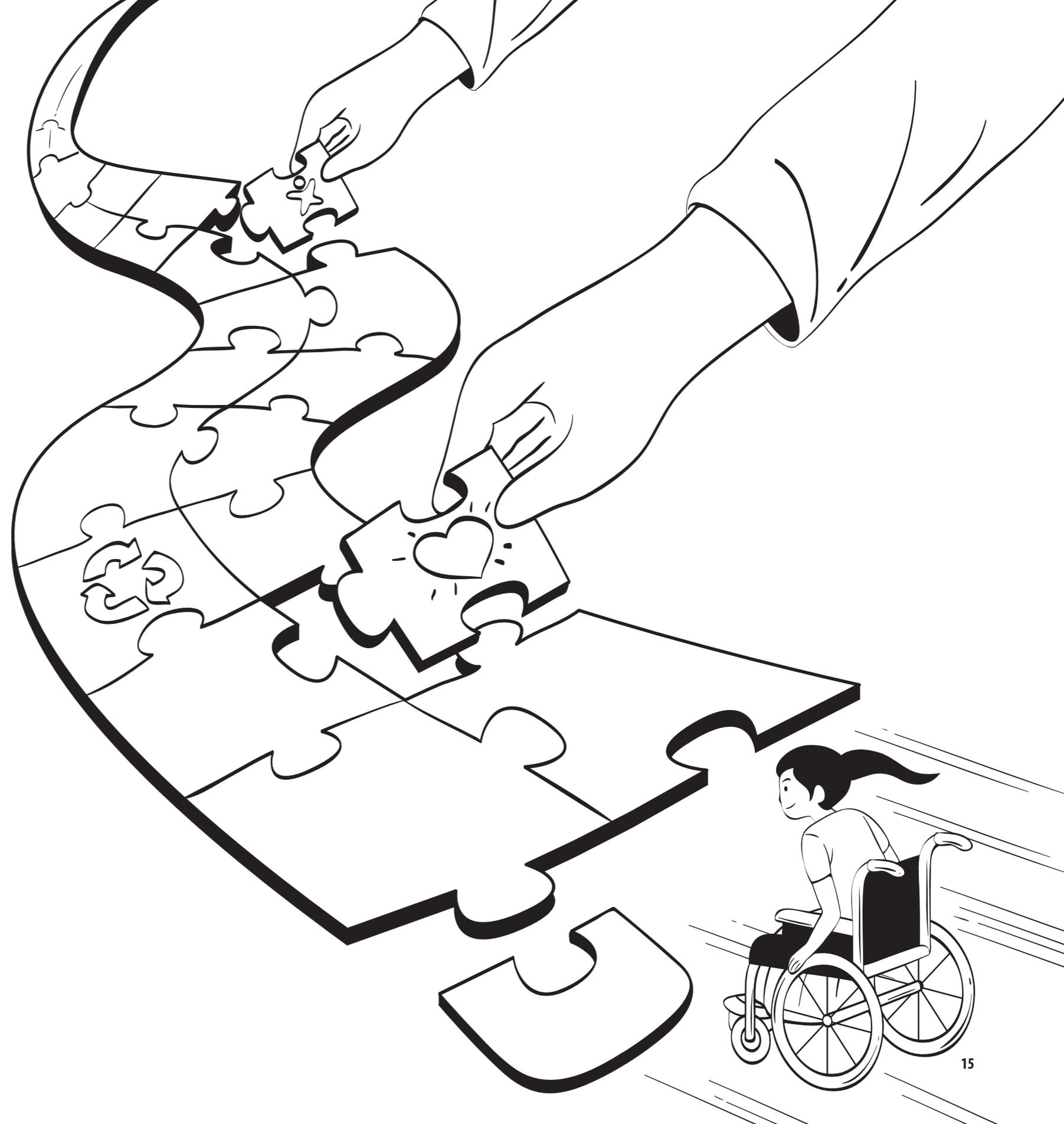
Taking a multi-faceted approach to individual well-being, an essential outcome is that individuals' *quality of life* is optimised in the form of a core set of diverse, essential needs. These needs are evaluated from individuals' own point of view, which gives credence to peoples' own awareness of what they need. This is important because researchers agree that the assessment of quality of life is subjective<sup>6</sup>, and because individuals perceive needs and give importance to them in different ways.

<sup>3</sup> The Social Service Sector Strategic Thrusts document may be found on NCCSS' website at <http://www.nccss.gov.sg/4ST>.

<sup>4</sup> 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>.

<sup>5</sup> Bronfenbrenner, U. (1986). *Ecology of the Family as a Context for Human Development: Research Perspectives*.

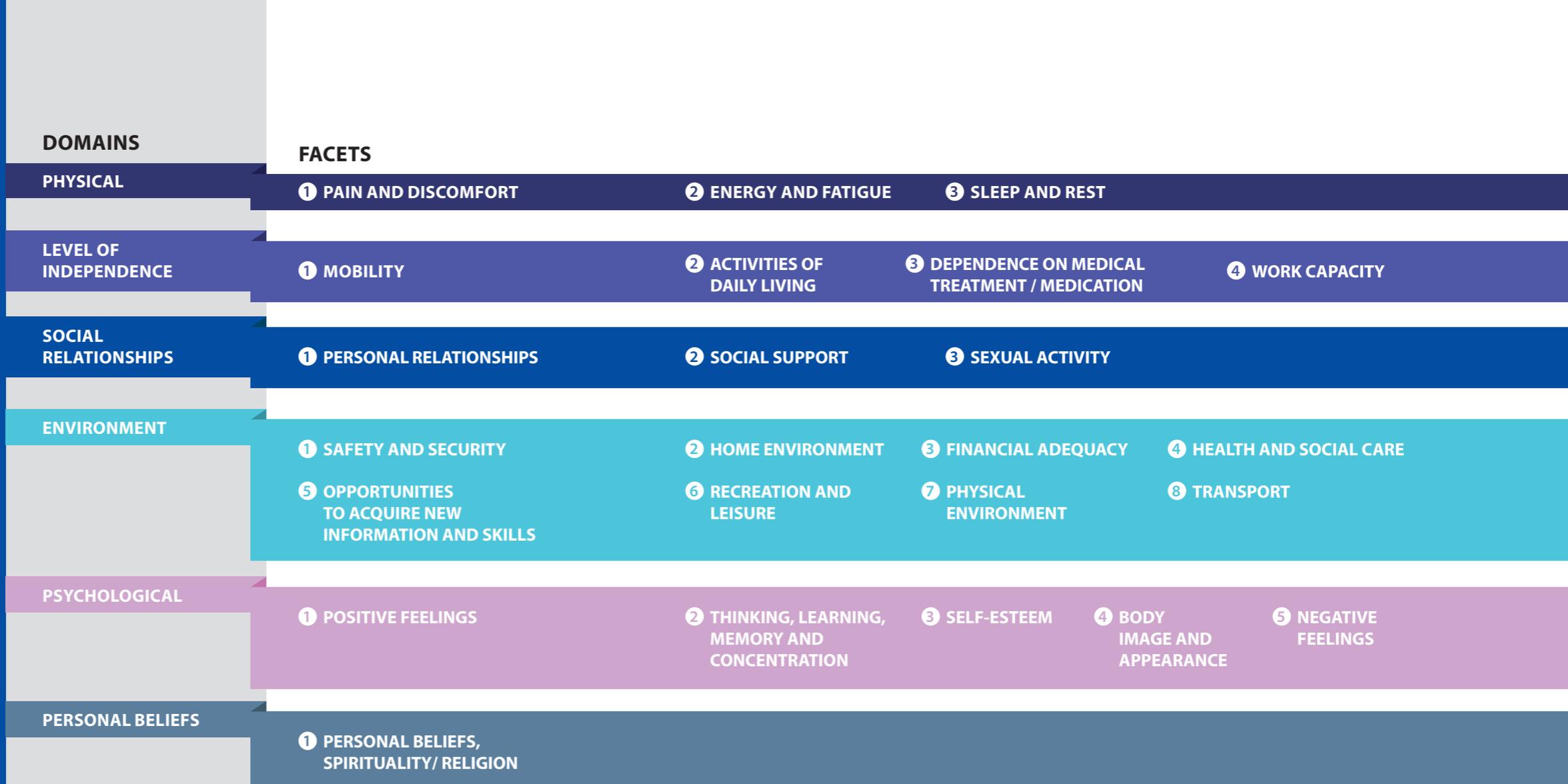
<sup>6</sup> Blatt, B. (1987). *The Conquest of Mental Retardation*; Taylor, S. & Racino, A. (1991). *Community Living: Lessons For Today*.



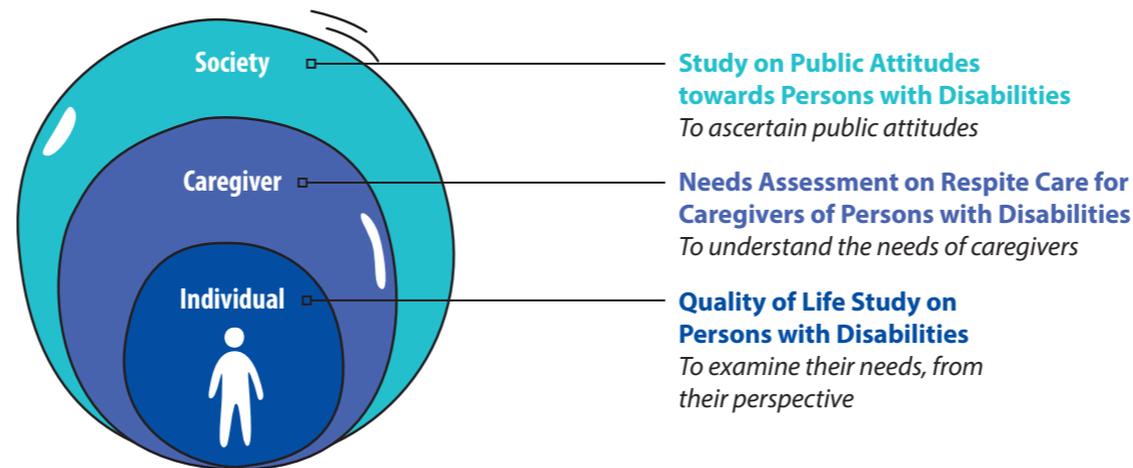
The World Health Organisation defines Quality of Life as such<sup>7</sup>:

“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**.



With this in mind, NCSS conducted three major studies to better understand the needs of persons with disabilities in Singapore. Each corresponds to an agent within the disability ecosystem:



<sup>7</sup> World Health Organization. (1993). Study Protocol for the World Health Organization Project to Develop a Quality of Life Assessment Instrument (WHOQOL).

# 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.

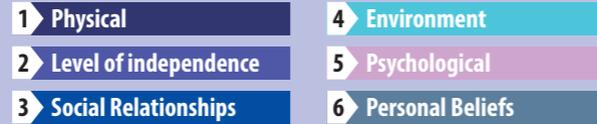
Collectively, these findings support existing knowledge and feedback, and will help the sector in deeper research, service planning efforts, public education and policy recommendations. In particular, the latest Enabling Masterplan, a 5-year roadmap that guides initiatives for the disability sector, adopted both the Quality of Life framework and findings in its strategic directions and recommendations<sup>8</sup>.

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<sup>9</sup>:



- 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<sup>10</sup>, 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.<sup>11</sup>

## KEY DESCRIPTIVES

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

<sup>\*</sup> Findings are self-reported.

<sup>^</sup> Includes those who acquired disabilities from accidents and illness.

<sup>+</sup> 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.

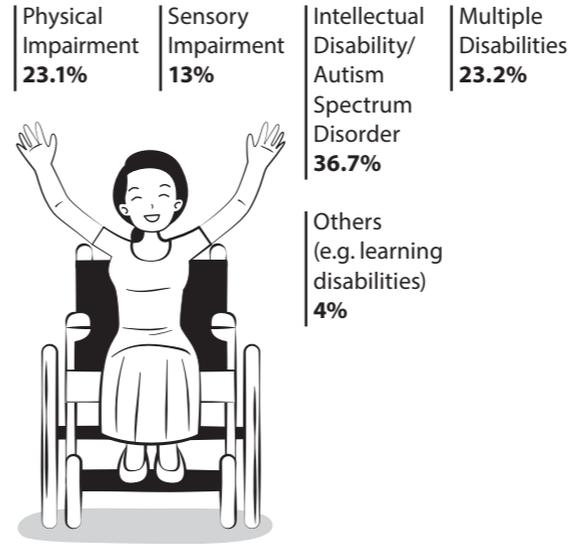
<sup>8</sup> The Enabling Masterplan 3 document can be found on NCSS' website at [https://www.ncss.gov.sg/NCSS/media/NCSS-Documents-and-Forms/EM3-Final\\_Report\\_20161219.pdf](https://www.ncss.gov.sg/NCSS/media/NCSS-Documents-and-Forms/EM3-Final_Report_20161219.pdf).

<sup>9</sup> More details on the domains, and facets under each domain, in Annex A.

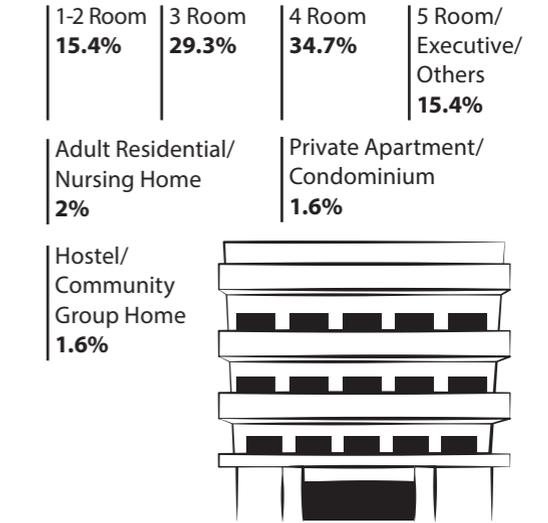
<sup>10</sup> SG Enable captures persons with disabilities (aged 18 and above) who have accessed services in government-funded social service organisations, special education schools or other schemes and support services administered by SG Enable at least once in their life. No other more representative national registry for persons with disabilities currently exists. Response Rate = 75.4%. Of 1,300 surveys distributed, 1,000 were completed and 981 responses used after cleaning.

<sup>11</sup> 50.9% were proxy responses.

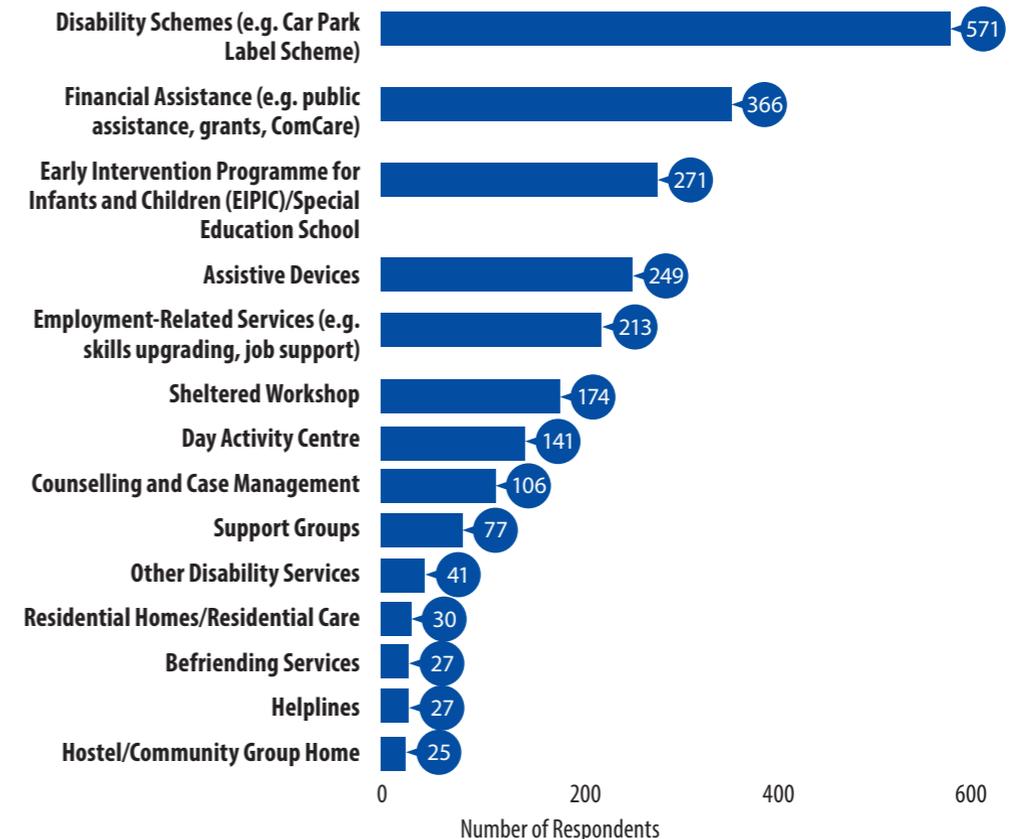
## RESPONDENT BREAKDOWN BY DISABILITY TYPE



## RESPONDENT BREAKDOWN BY HOUSING TYPE



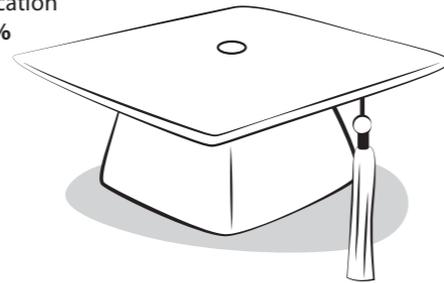
## RESPONDENTS WHO HAVE USED/ARE ACCESSING SERVICES<sup>^</sup>



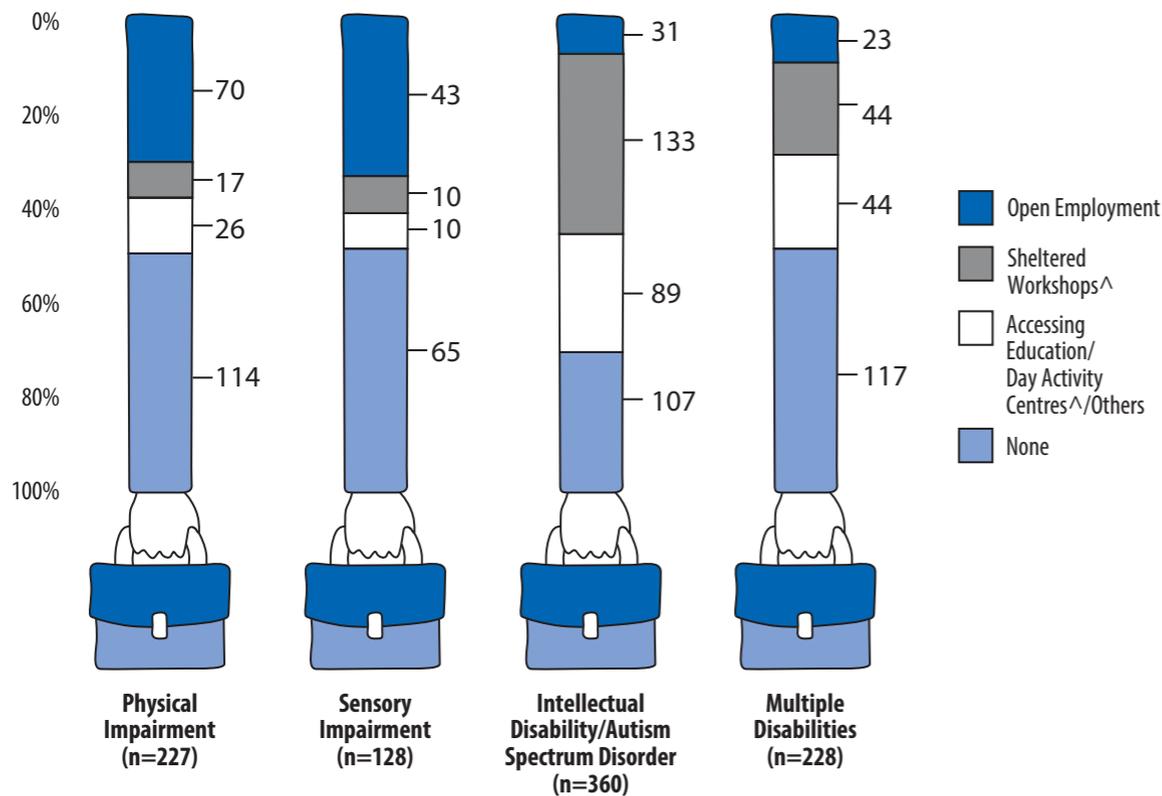
<sup>^</sup> Respondents were allowed to indicate their attendance of more than one service.

**RESPONDENT BREAKDOWN BY EDUCATION**

None 12.2%	Primary School 17.2%	Secondary School 13.3%	Graduated from SPED 42.1%	Institute of Technical Education 4.8%
Polytechnic 4%	Junior College/Pre-University 1.6%	University Degree Holders 4.2%	Others 0.6%	



**RESPONDENT BREAKDOWN BY EMPLOYMENT AND DISABILITY TYPE**



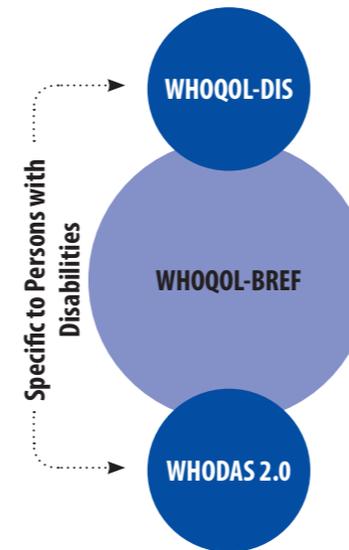
^ For more information on what these terms refer to, please refer to Annex B.

**COMPARISON TO THE GENERAL POPULATION**

As a basis for comparison, NCSS also obtained a representative sample (n = 942) of the general population through the Department of Statistics<sup>12</sup>.

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.

**QUALITY OF LIFE**



**WHOQOL-BREF<sup>13</sup>**

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*<sup>14</sup>. 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 AREAS SURVEYED BY NCSS**

- 
1. Demographics
  2. Desired Areas of Improvement
  3. Perception of Health Status and Health Conditions
  4. Service-Related Questions

Facet	Areas Covered
Autonomy	Feeling in control of one's life 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

<sup>12</sup> 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%.

<sup>13</sup> 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](http://www.who.int/mental_health/media/en/76.pdf).

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

### WHODAS 2.0 (WHO DISABILITY ASSESSMENT SCHEDULE)<sup>15</sup>

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

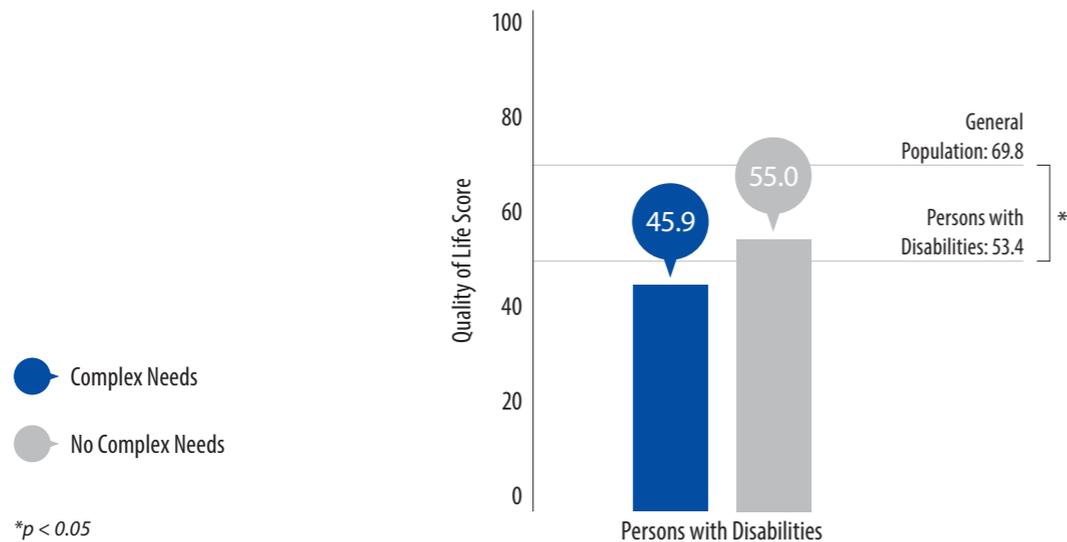
### KEY FINDINGS

#### 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).

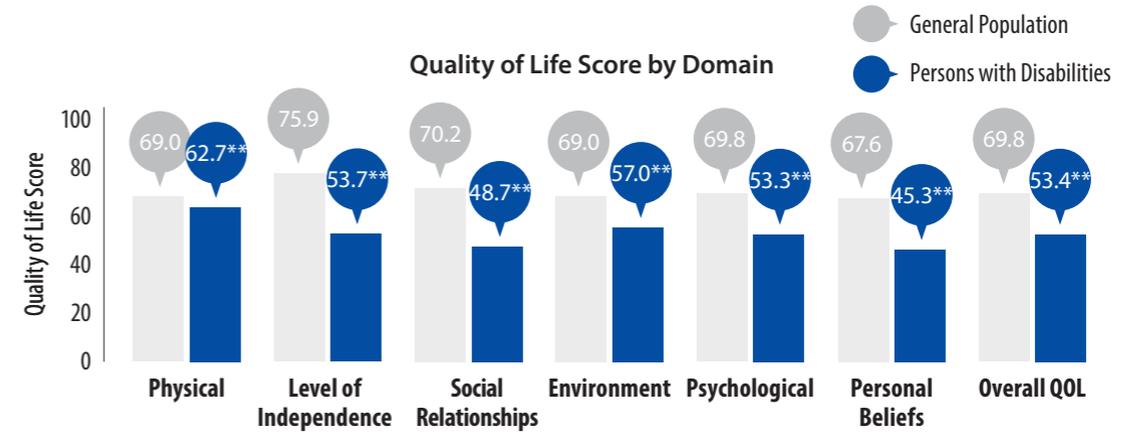
Quality of Life Score by Presence of Complex Needs



<sup>15</sup> The WHODAS 2.0 has been tested in different cultural settings and health populations and has robust psychometric properties (Gold, 2014).

#### Finding #2

Persons with disabilities scored lower than the general population across all quality of life domains<sup>^</sup>, especially on *level of independence, personal beliefs* and *social relationships*, particularly in the area of social support from friends.

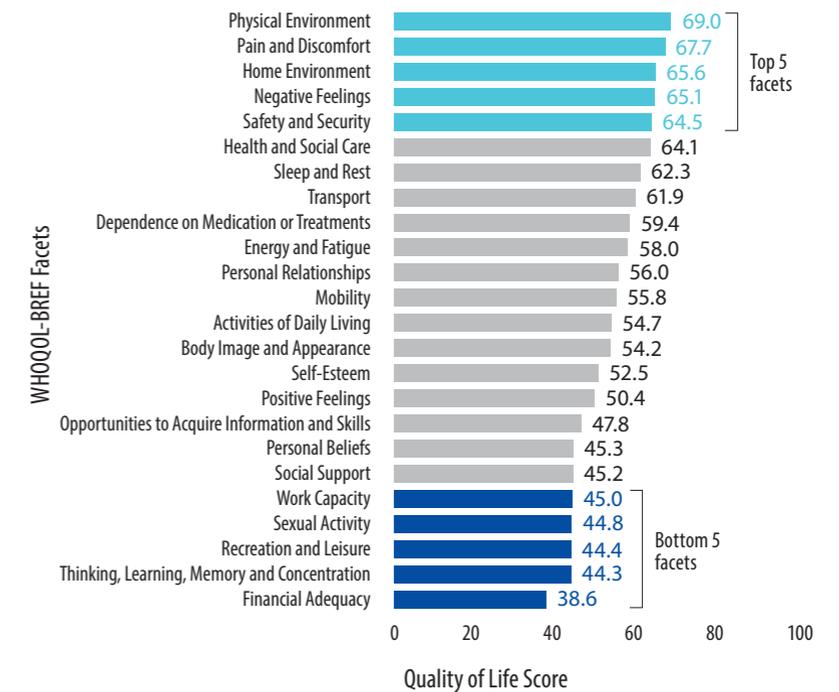


\*\*p < 0.01. A Multivariate Analysis of Variance was performed on the six domains related to quality of life (DV) and group membership (IV).

At the facet level<sup>^</sup>, persons with disabilities reported the:

- Worst scores in *financial adequacy and thinking, learning, memory and concentration*
- Best scores in *physical environment and pain and discomfort*

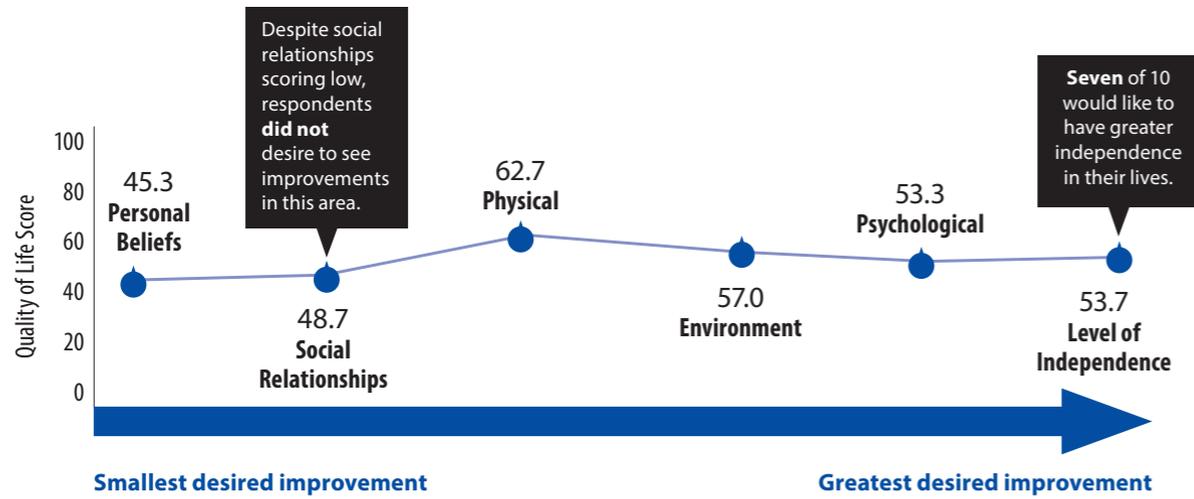
Quality of Life Score by Facet



<sup>^</sup> For more information on the Quality of Life domains and facets, please refer to **Annex A**.

**Finding #3**

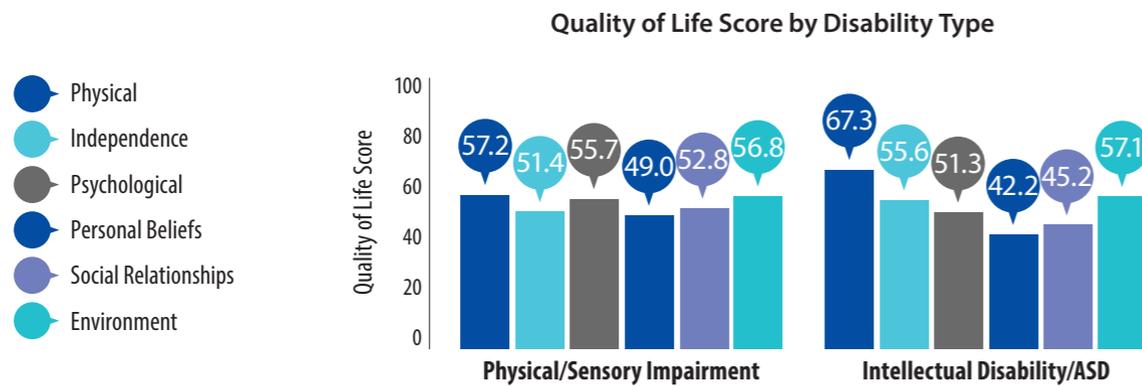
When asked about which areas they wished to see improved, persons with disabilities prioritised *level of independence*, followed by *psychological well-being* and in their *environmental resources*.



**Finding #4**

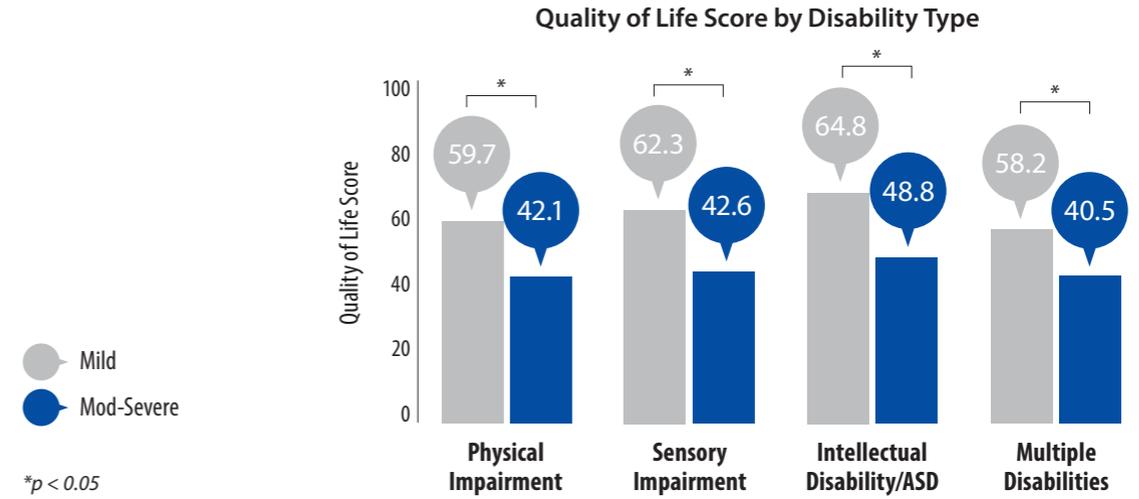
Depending on disability type, respondents reported slightly different needs:

- Those with physical or sensory impairments experienced lower quality of life in terms of their *personal beliefs, social relationships and psychological well-being*
- Those with intellectual disability and Autism Spectrum Disorder experienced lower quality of life in the domains of *personal beliefs, level of independence and social relationships*



**Finding #5**

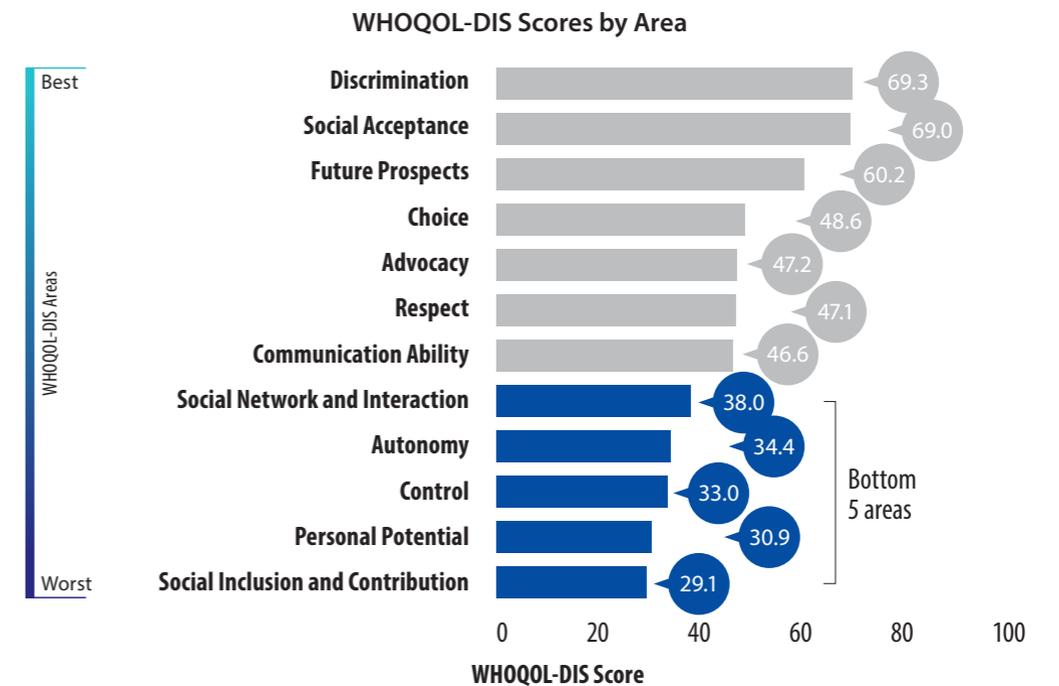
Regardless of disability type, persons with *moderate-severe disabilities* experienced lower quality of life than those with mild disabilities.



**Finding #6**

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.



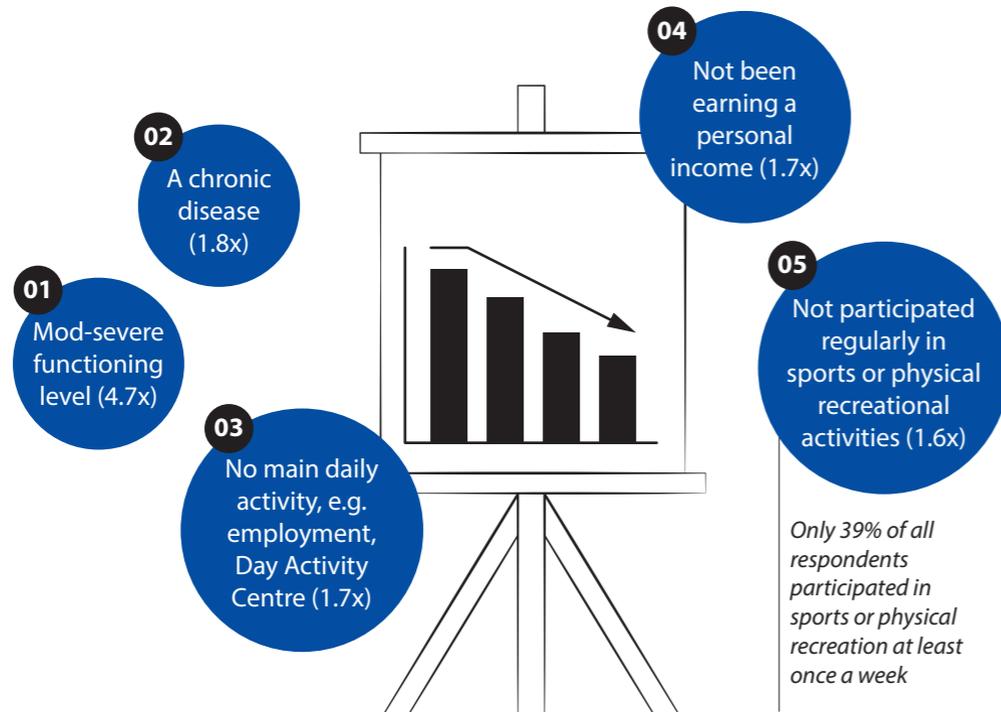
24-year-old full-time national serviceman **Samuel** aspires to find work in the financial sector and boost his employability by earning a degree. Having had positive working experiences with Mount Alvernia Hospital and in the Air Force, he sums up his thoughts about how persons with disabilities can 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**

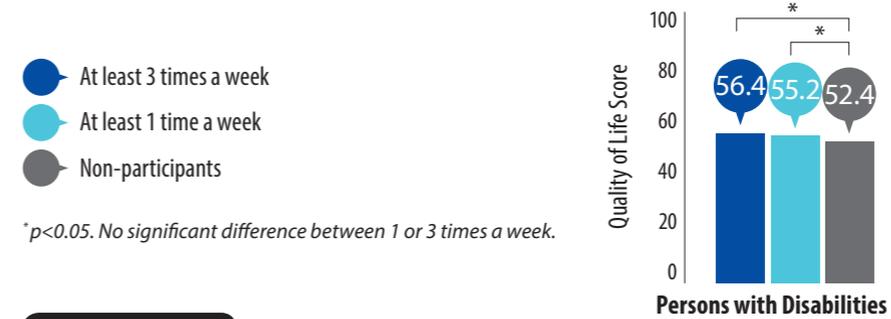
Respondents were more likely to have a lower quality of life if they had:<sup>^</sup>



<sup>^</sup> **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.

Respondents who participated in sports or physical recreation reported higher quality of life than those who did not.

**Quality of Life Score by Frequency of Participation in Sports/Physical Recreation**



**Finding #8**

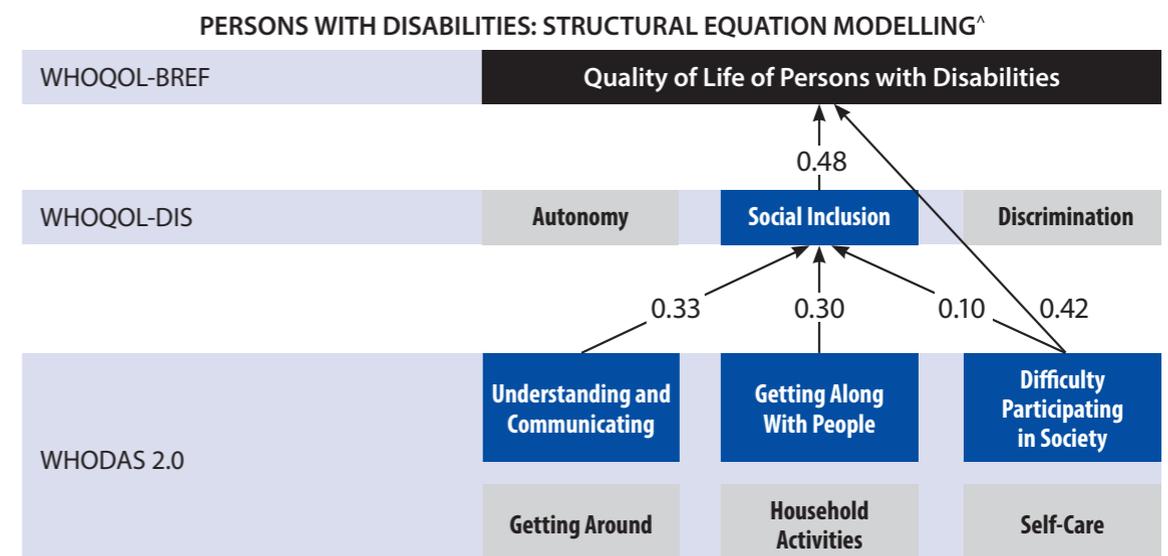
In holistically improving the areas outlined in the WHOQOL-BREF, addressing *social inclusion* when designing initiatives can achieve the greatest effect.

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.

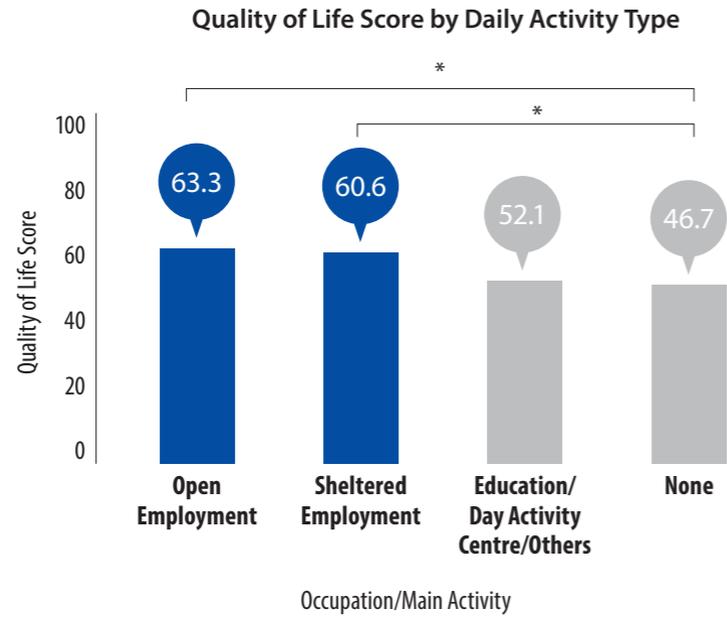
A **Structural Equation Modelling (SEM)** is used to understand the relationship between factors, particularly that between observable and unobservable variables. It provides numerical estimates that indicate the strength of such relationships.



<sup>^</sup> A simplified representation of Structural Equation Modelling – Multiple Indicators Multiple Causes Method.

**Finding #9**

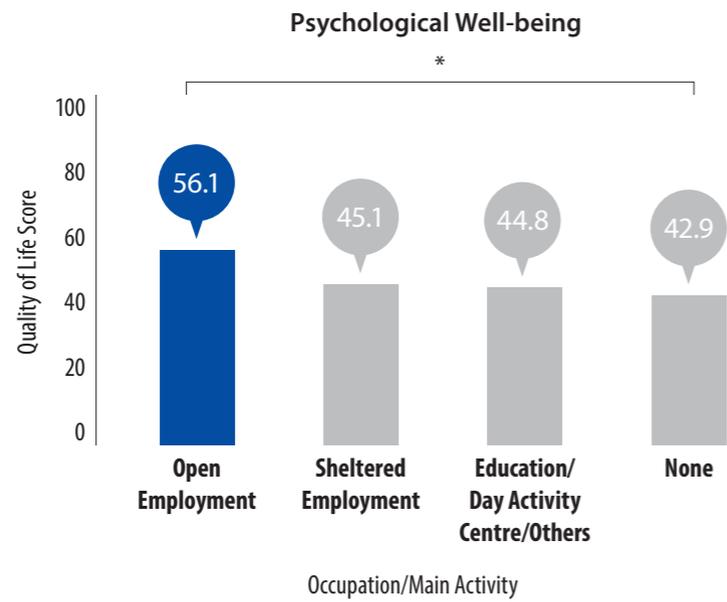
Persons with disabilities who were *not engaged in a main daily activity*, particularly employment, experienced lower quality of life.



\*p < 0.05

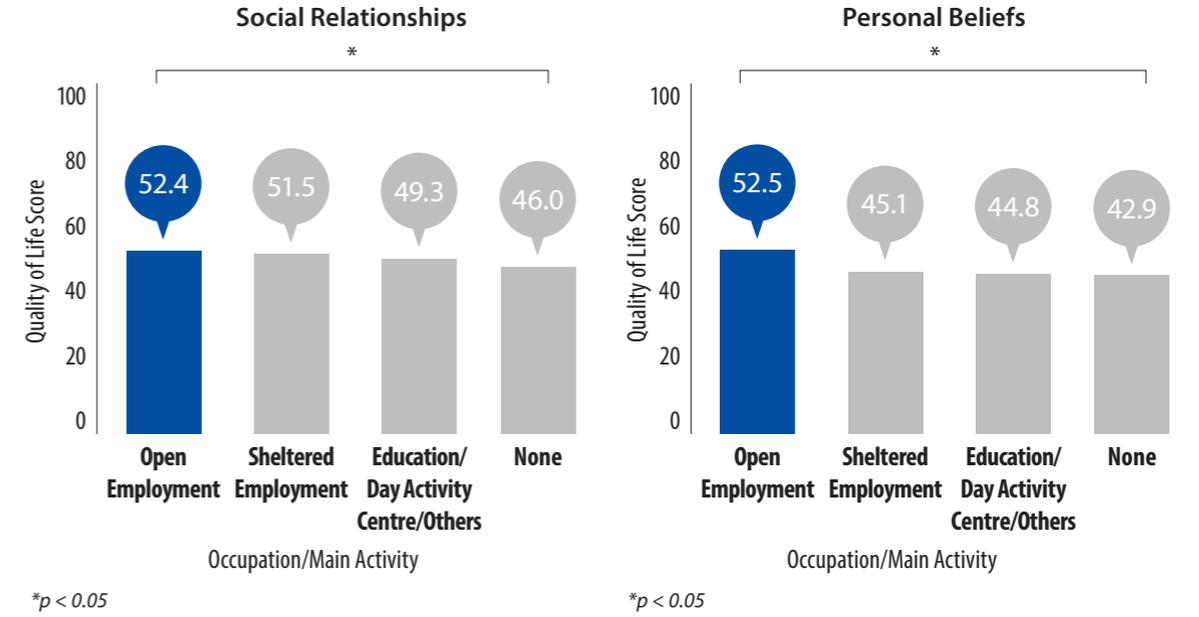
Occupation/Main Activity

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



\*p < 0.05

Occupation/Main Activity

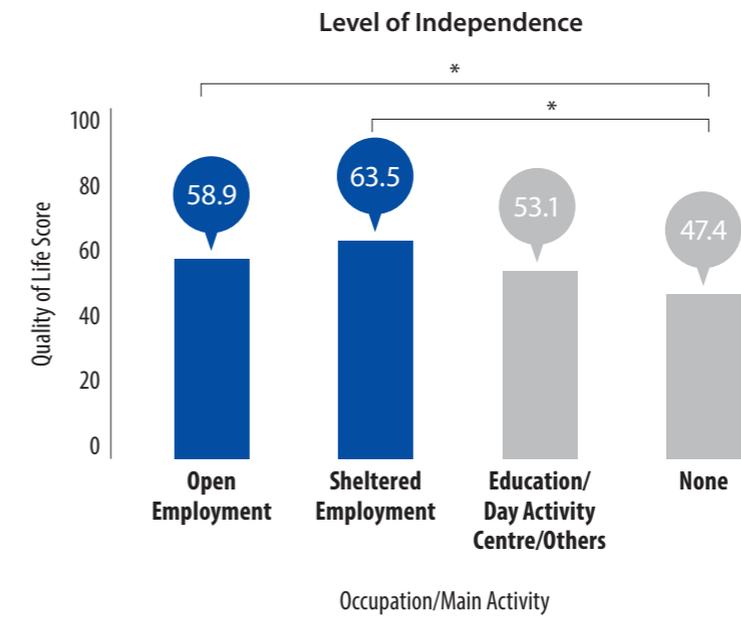


\*p < 0.05

\*p < 0.05

**Finding #10**

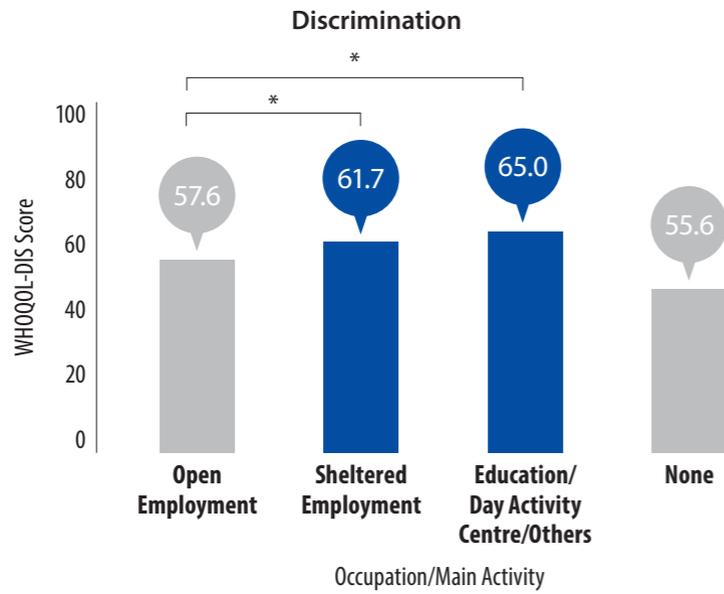
Those in employment reported a *higher level of independence*.



\*p < 0.05

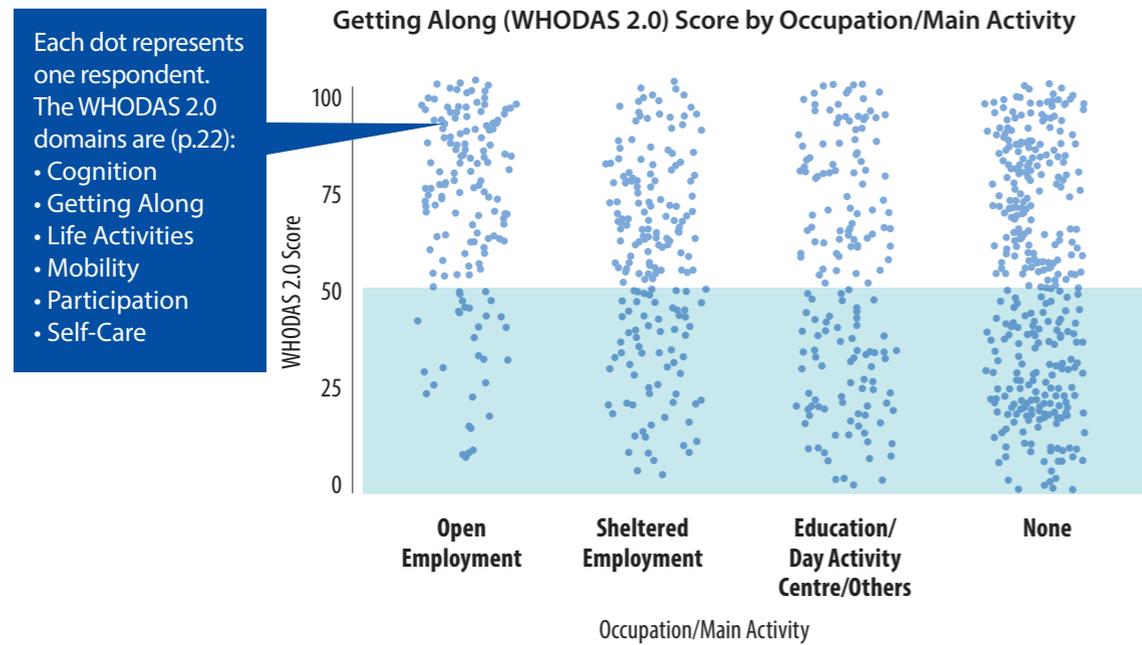
Occupation/Main Activity

However, those in open employment tended to feel *discriminated against*.



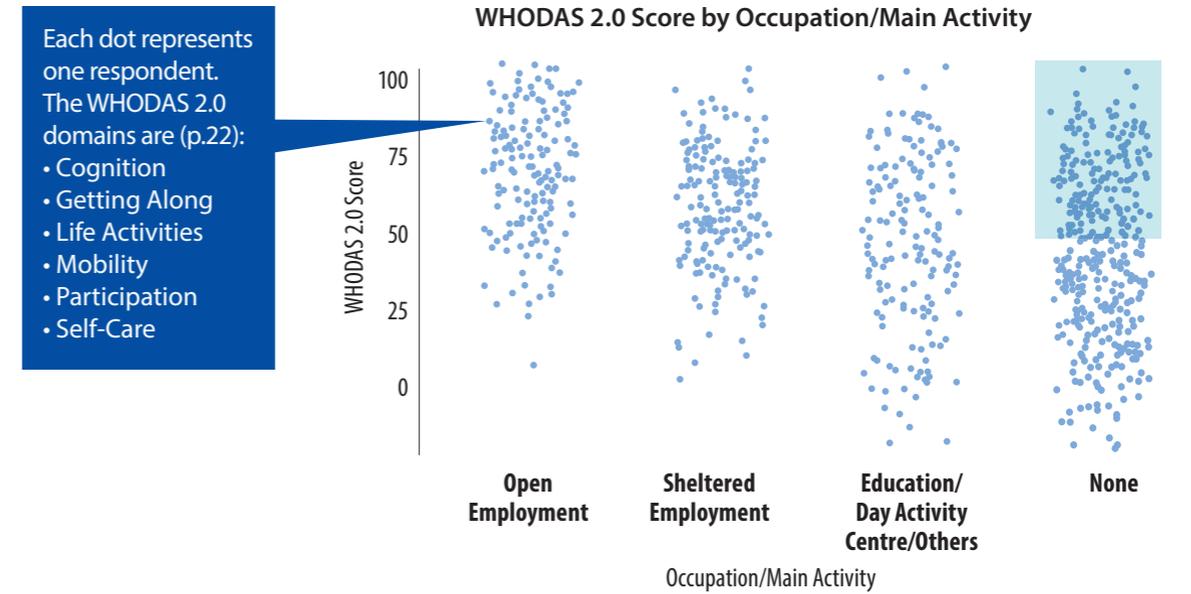
\*p < 0.05

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



**Finding #11**

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<sup>16</sup> 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<sup>17</sup>, stress<sup>18</sup> or decreased work participation in general<sup>19</sup>.

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<sup>20</sup>.

## 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.<sup>21</sup>

## FOCUS GROUP DISCUSSIONS

Six focus group discussions were held with caregivers<sup>22</sup> 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<sup>23</sup>, and then by service type<sup>24</sup>. 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<sup>25</sup>.

## KEY DESCRIPTIVES

### AGE OF CAREGIVER

<35	35-44	45-54	55-64	>65
11.3%	34.3%	32.5%	13.6%	8.3%



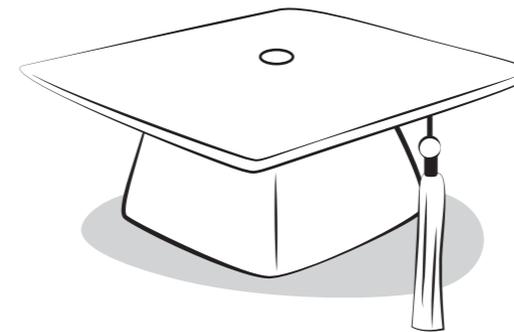
### RELATION OF CAREGIVER TO CARE RECIPIENT

Parent	Sibling	Grandparent	Others
90%	6.0%	1.0%	3.0%



### EDUCATION LEVEL OF CAREGIVER

Primary	Secondary	Junior College	Tertiary
13.2%	44.3%	7.8%	34.8%



### HOUSEHOLD INCOME

<\$1000	\$1000 < \$3000	\$3000 < \$6000	>\$6000
15.5%	36.3%	25.5%	22.7%



<sup>16</sup> 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.

<sup>17</sup> 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.

<sup>18</sup> 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.

<sup>19</sup> Chan, Ostbye, & Malhotra (2013) noted that in Singapore, 47% of caregivers are not working and of those who did, 29% indicated that they had to leave work at least once in six months for care recipients' doctor's appointments.

<sup>20</sup> Lam, L. (2017, February 20). Singapore Budget 2017: Integrating Disabled into Workforce and Supporting Caregivers Focus of New Govt Masterplan.

<sup>21</sup> Where real stories, accounts or quotes are used, names have been changed for reasons of privacy.

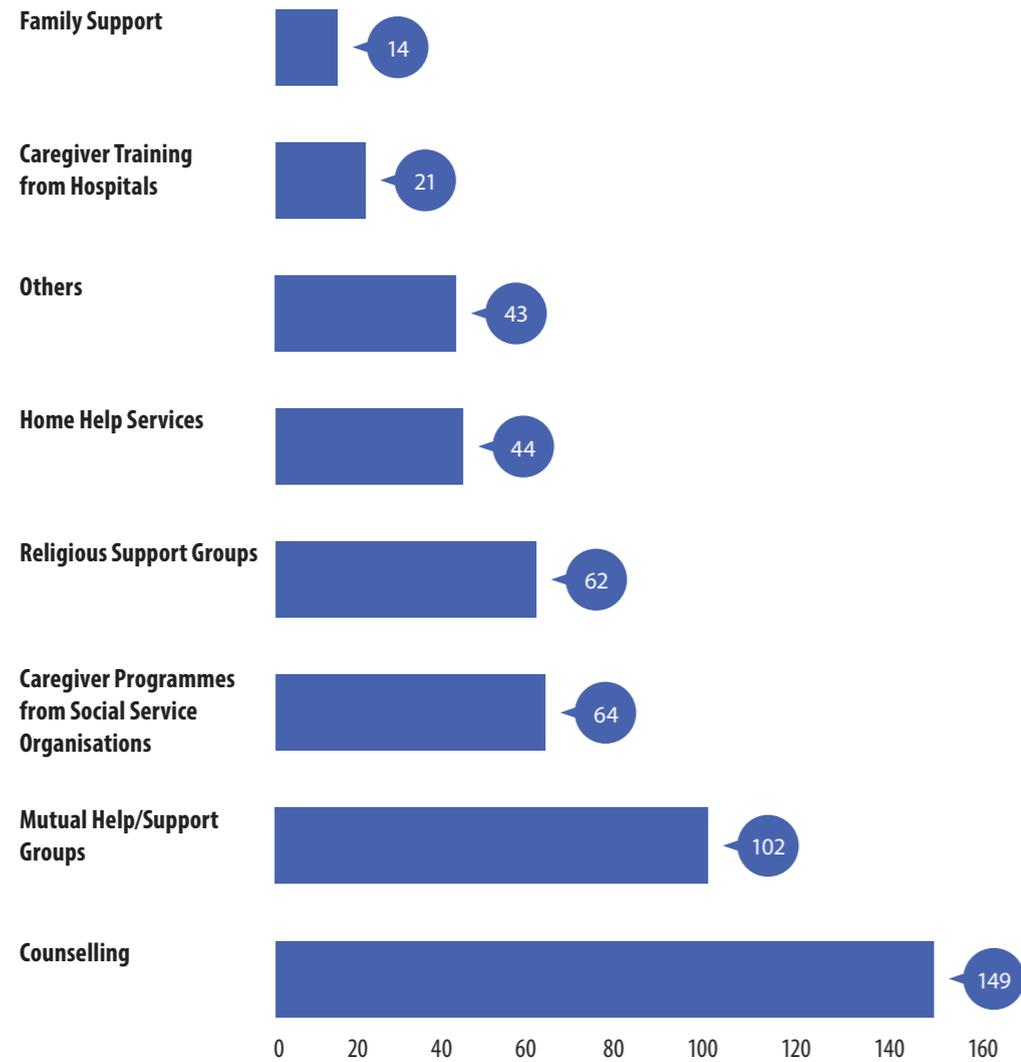
<sup>22</sup> Caregiver contacts were provided by relevant social service organisations.

<sup>23</sup> 0-6 years old, 7-21 years, 19 years and above.

<sup>24</sup> Early Intervention Programme for Infants and Children, Special Education as well as training places such as Day Activity Centres and Sheltered Workshops.

<sup>25</sup> Response Rate: 49.3%. Of 1,600 surveys distributed, 967 surveys were returned, of which 178 were considered invalid (12 nil returns, 166 incompletely filled).

CAREGIVER SUPPORT SERVICES ACCESSED<sup>^</sup>



<sup>^</sup> Caregivers were allowed to select more than one service.

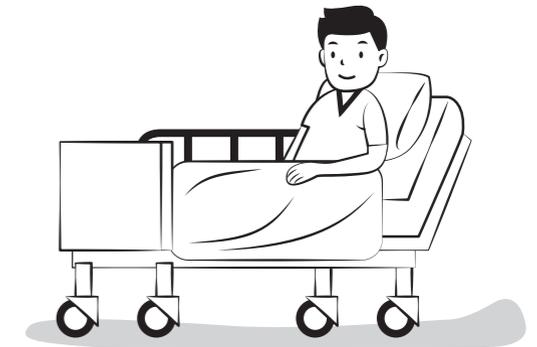
CARE RECIPIENT'S DISABILITY TYPE

Physical Impairment 13%	Sensory Impairment 3%	Intellectual Disability 32%
Autism Spectrum Disorder 29%	Multiple Disabilities 22%	



SEVERITY OF CARE RECIPIENT'S DISABILITY

Mild 39.4%	Moderate 49.1%	Severe 11.5%
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The survey probed into respondents' caregiving and care recipient profiles as well as his or her knowledge, perception and utilisation of respite care. Three instruments were also included in the questionnaire.

**CAREGIVER STRAIN INDEX (CSI)<sup>26</sup>**

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)<sup>27</sup>**

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.<sup>28</sup>

**KESSLER-6 (K6)<sup>29</sup>**

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.

<sup>26</sup> 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 a = 0.87.

<sup>27</sup> 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-Lopez & 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 a = 0.93.

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

<sup>29</sup> A truncation of K10 (Kessler et al. 2003). More information on the scale can be found at <https://www.gem-measures.org/public/DownloadMeasure.aspx?mid=35> In this study, Cronbach a = 0.91.

KEY FINDINGS

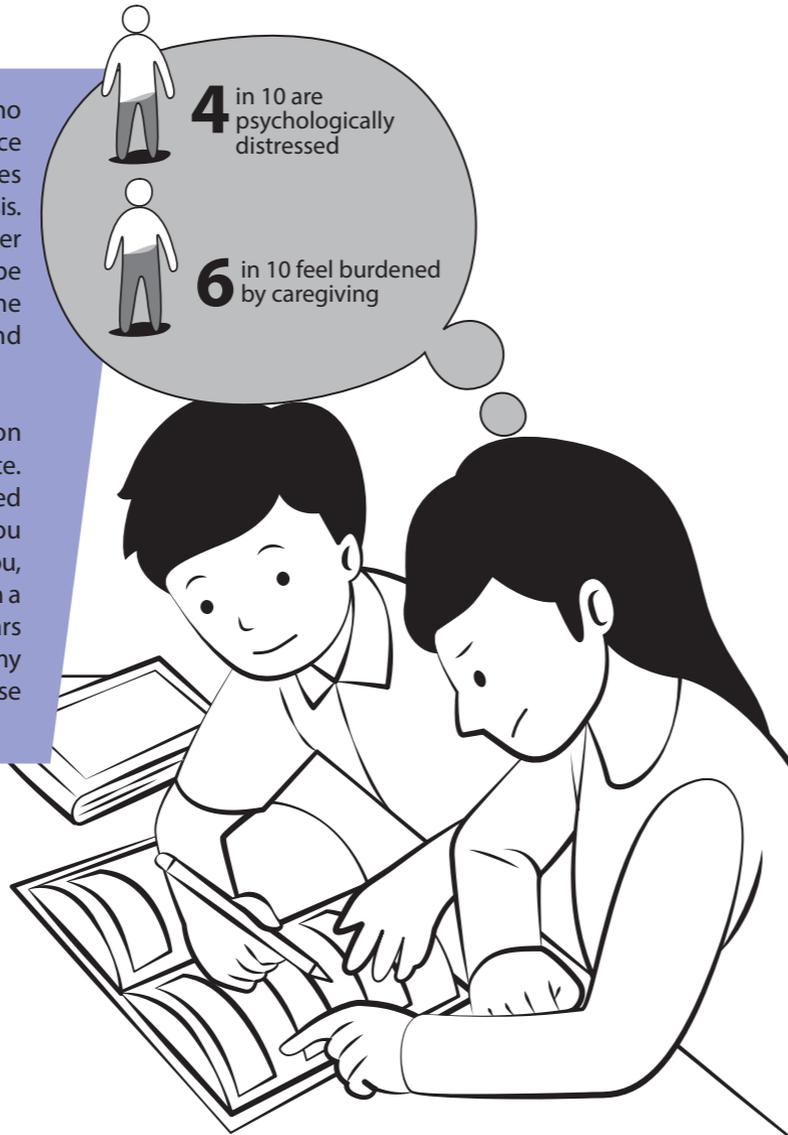
Finding #1

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.”

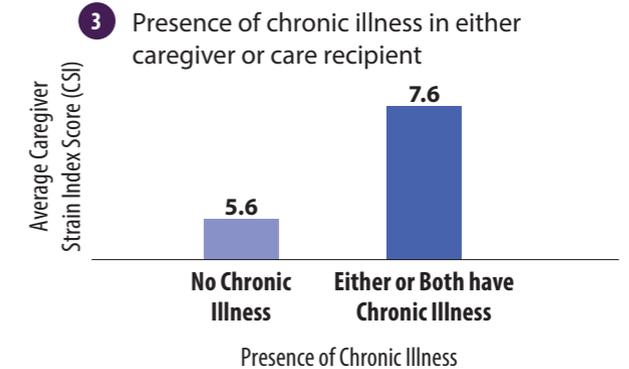
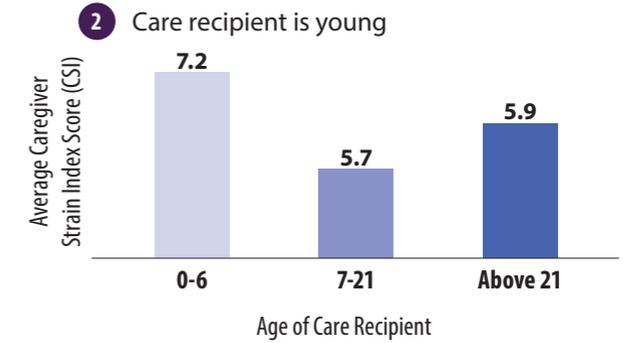
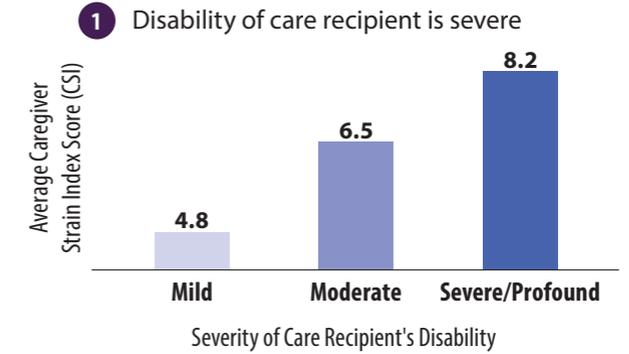


4 in 10 are psychologically distressed

6 in 10 feel burdened by caregiving

Finding #2

Factors Contributing to High Caregiver Stress



“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

- 4 Care recipient has Autism Spectrum Disorder or intellectual disability
- 5 Low average household income
- 6 High education

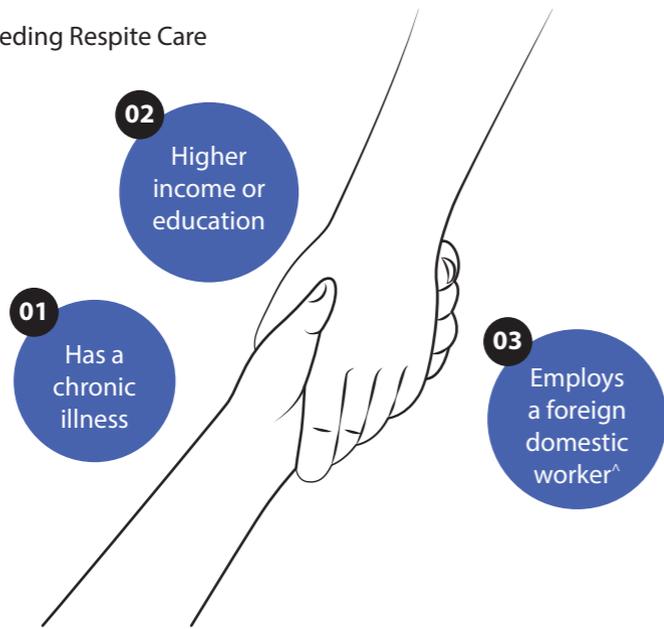


Having a degree did not shield **Anne** from the struggle of caring for her son, 7-year-old Cody. She treasures spending time together with Cody, whether at picnics, running and biking, or bringing him to parties where she frequently tells family and friends about him. However, there was a time when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

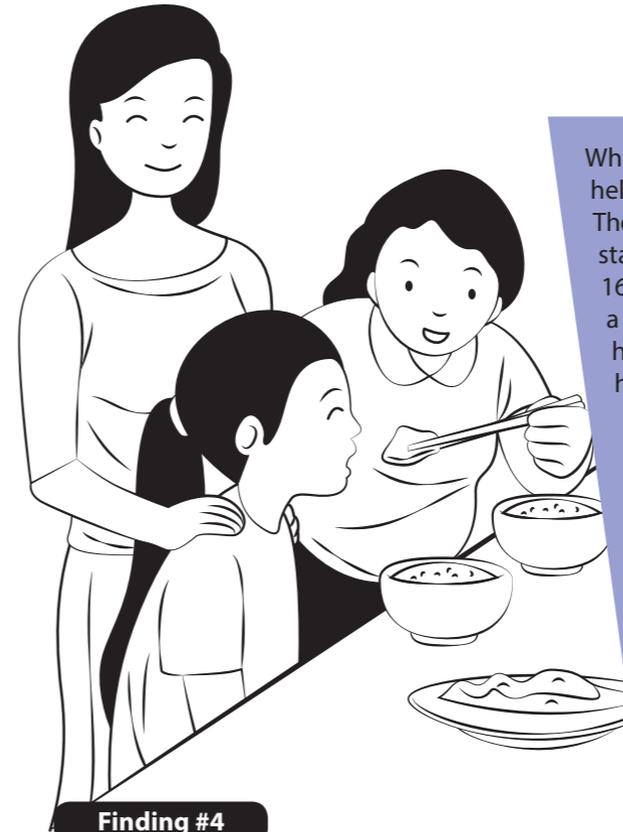
“The first year was difficult for me. ‘Cause he was my oldest son so when he came I was very idealistic...I want to be a perfect, cool mum...and then when we found out that he had Autism the world crumbled. Within a year, we were so busy with therapies and trying to learn everything that I closed off. I think [that] my coping [period] was one year, after that I came out publicly, talk[ed] 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

Profile of Caregiver Needing Respite Care



^ 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.



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!”

Finding #4

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).



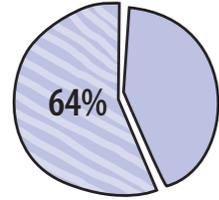
Those who have encountered the term "respite care" found out about it through social service providers



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

**Finding #5**

Caregivers regarded *child safety, affordability and having trained personnel* as important in respite care services.

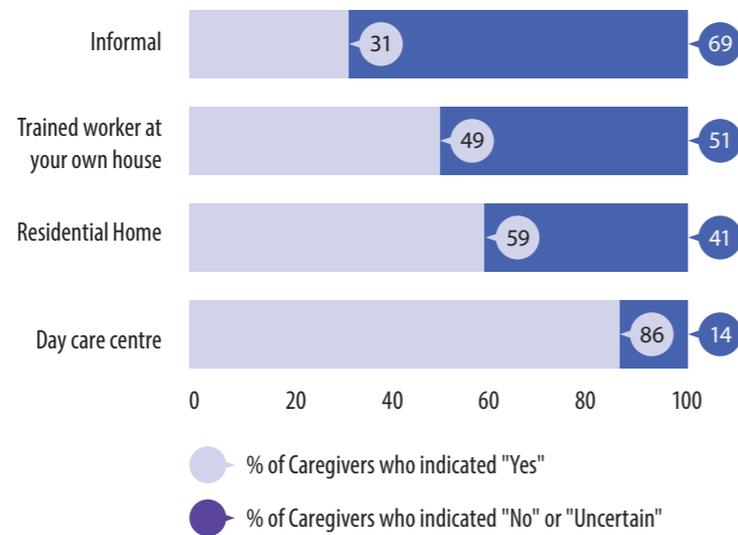


64% feel that respite carers should be trained/social workers.

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

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.

Acceptance of Types of Respite Care

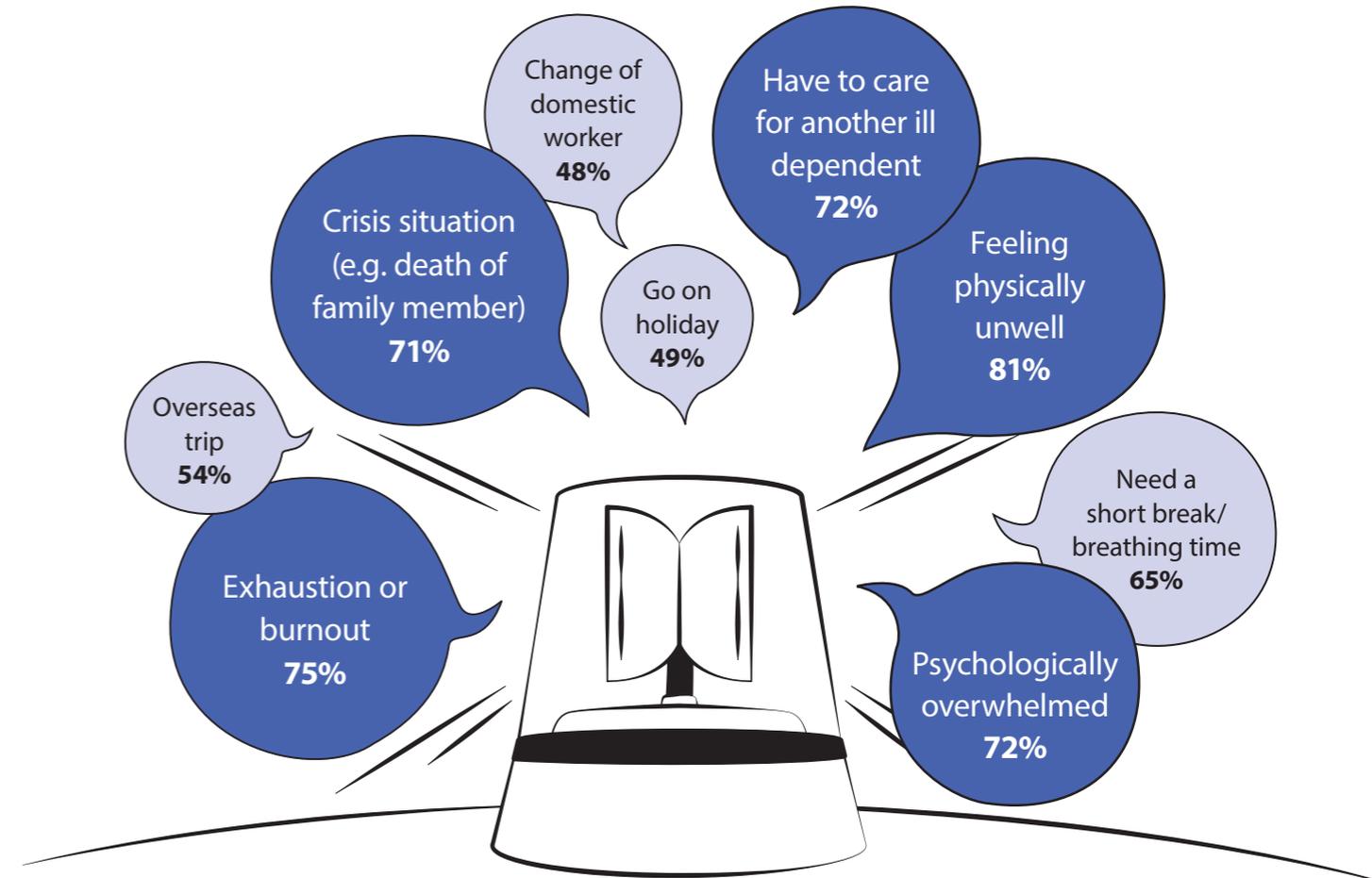


**Finding #6**

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.

**SITUATIONS REQUIRING RESPITE CARE**



# 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.



The See The True Me campaign educates the public on communication tips and support strategies for persons with disabilities, and encourages them to see persons with disabilities for who they are and include them in society.

Insights from this study informed strategies for NCSS to work towards building a more inclusive society, such as NCSS' 5-year disability awareness and public education campaign supported by Tote Board entitled "See The True Me".

## 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

30 Where real stories, accounts or quotes are used, names have been changed for reasons of privacy.  
 31 Participants had a range of physical and sensory impairments as well as Autism Spectrum Disorder, and acquired them at birth. They were adults who are home-based and not institutionalised, as they would have ample chance to interact with the general population.  
 32 Randomised sampling was performed on the 50 geographical areas that are equally distributed across Singapore, following which quotas were set by the respective house types within each area. Only Singapore Citizens and Permanent Residents aged 18 to 69 years old were sampled.

## METHOD

The study was conducted in three stages, comprising a quantitative survey as well as pre- and post-survey qualitative components<sup>30</sup>.

### PRE-SURVEY QUALITATIVE

Five focus group discussions and an in-depth discussion were conducted with persons across a range of disabilities<sup>31</sup>. 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.

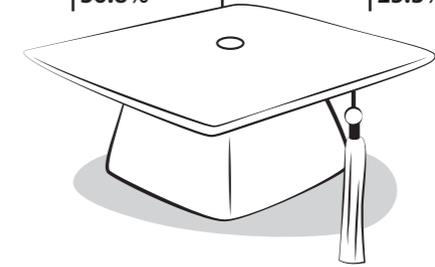
### QUANTITATIVE SURVEY

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<sup>32</sup>. 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.<sup>33</sup>

The survey was done face-to-face and self-administered<sup>34</sup>. Beyond demographics such as age and ethnicity, a composite instrument was constructed based on questions from a variety of scales<sup>35</sup> and pilot-tested for reliability and validity (n = 200).

### EDUCATION LEVEL

No formal education/ Primary	Secondary/ Institute of Technical Education	Junior College/ Polytechnic	Degree/ Postgraduate Degree/ Others
16.4%	36.8%	21.6%	25.3%



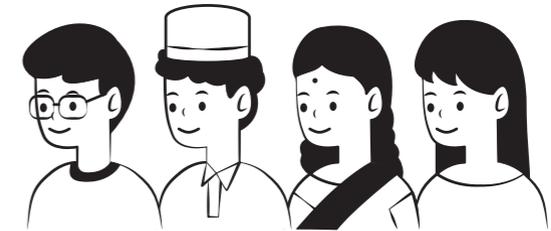
### AGE

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



### ETHNICITY

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



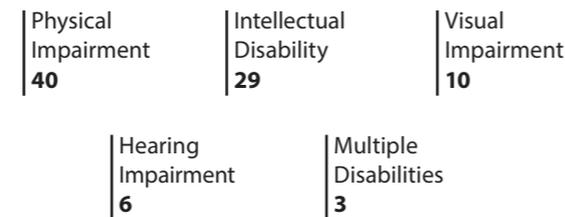
33 Out of 1,500 contacts. Response Rate = 93.3%.  
 34 In cases where participants were illiterate, responses were assisted. The "next birthday" method of random respondent selection was used to select a member of each household whose birthday will come up next.  
 35 Scales consulted:  
**Instruments**  
 Disability Social Distance Scale (DSDS)  
 Scale of Attitudes Toward Disabled Persons (SADP)  
 Issues in Disability Scale (IDS)  
 Multidimensional Attitudinal Scale (MAS)  
**Study**  
 Tringo (1970)  
 Antonak (1982)  
 Makas, Finnerty-Fried, Sigafos & Reiss (1988)  
 Findler, Vilchinsky & Werner (2007)

Respondents were queried on their attitudes, perceptions of, exposure to and knowledge regarding persons with disabilities. In particular, attitude scores were measured along on three dimensions: *Affect*, *Behaviour* and *Cognition*<sup>36</sup>.

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

<sup>^</sup>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 Respondent Breakdown



**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.

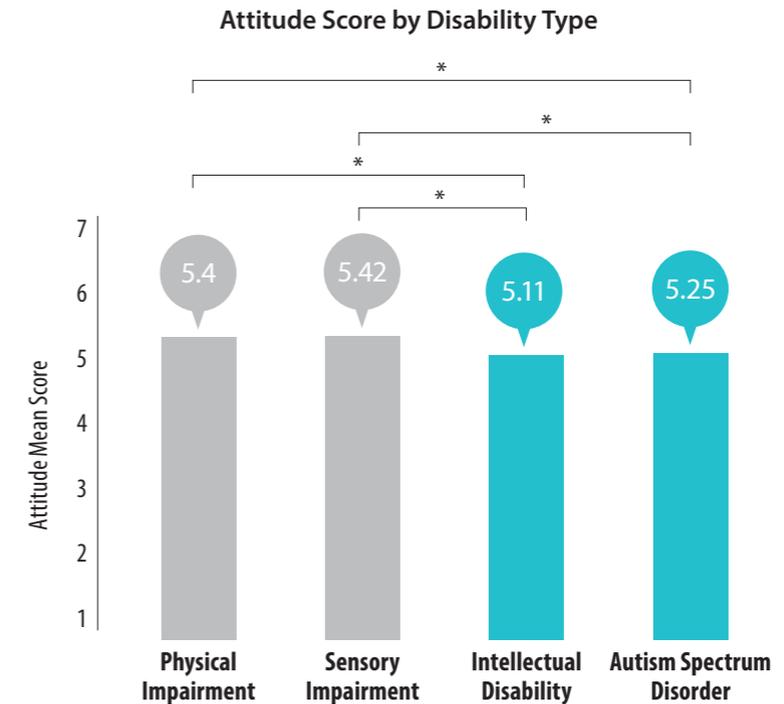
A total of 88 respondents participated in the dialogues, which helped provide a better understanding of barriers to the inclusion of persons with disabilities as well as potential solutions in specific domains such as employment.

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

**KEY FINDINGS**

**Finding #1**

Public attitudes towards persons with *intellectual disability* or *Autism Spectrum Disorder* were less favourable than those with physical or sensory impairment.



\*p < 0.05

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**

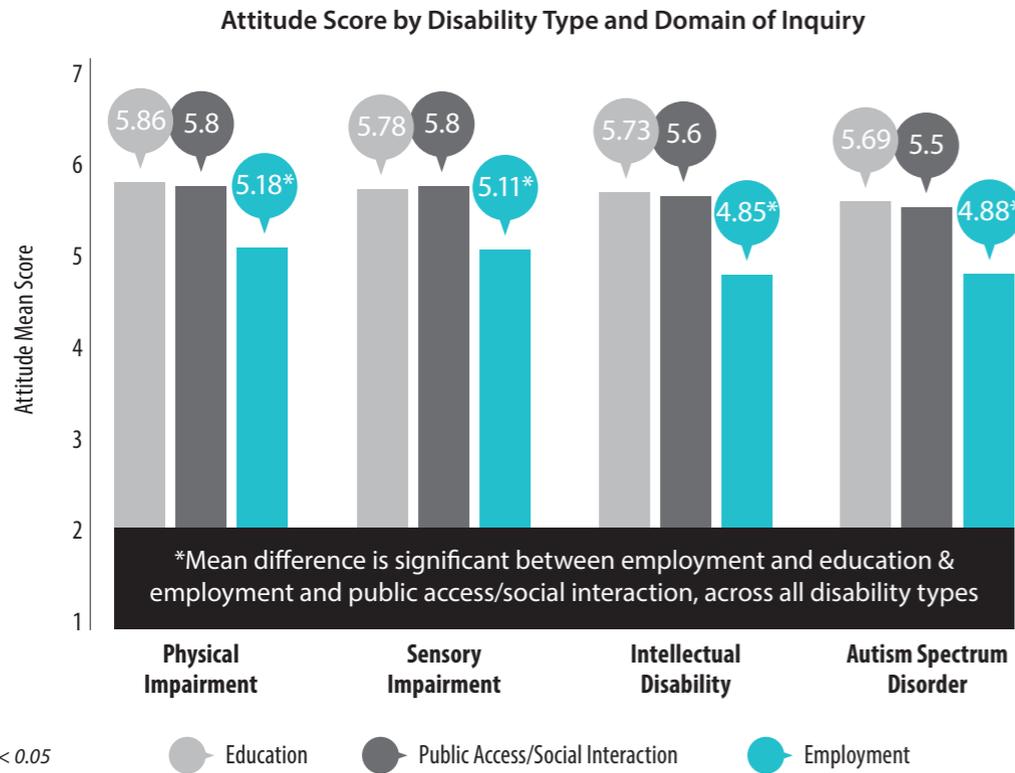
"They don't see us as able bodied...sometimes the lecturer will pity...and will give good grades."

– Focus group participant with hearing impairment

<sup>36</sup> 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).

**Finding #2**

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*:



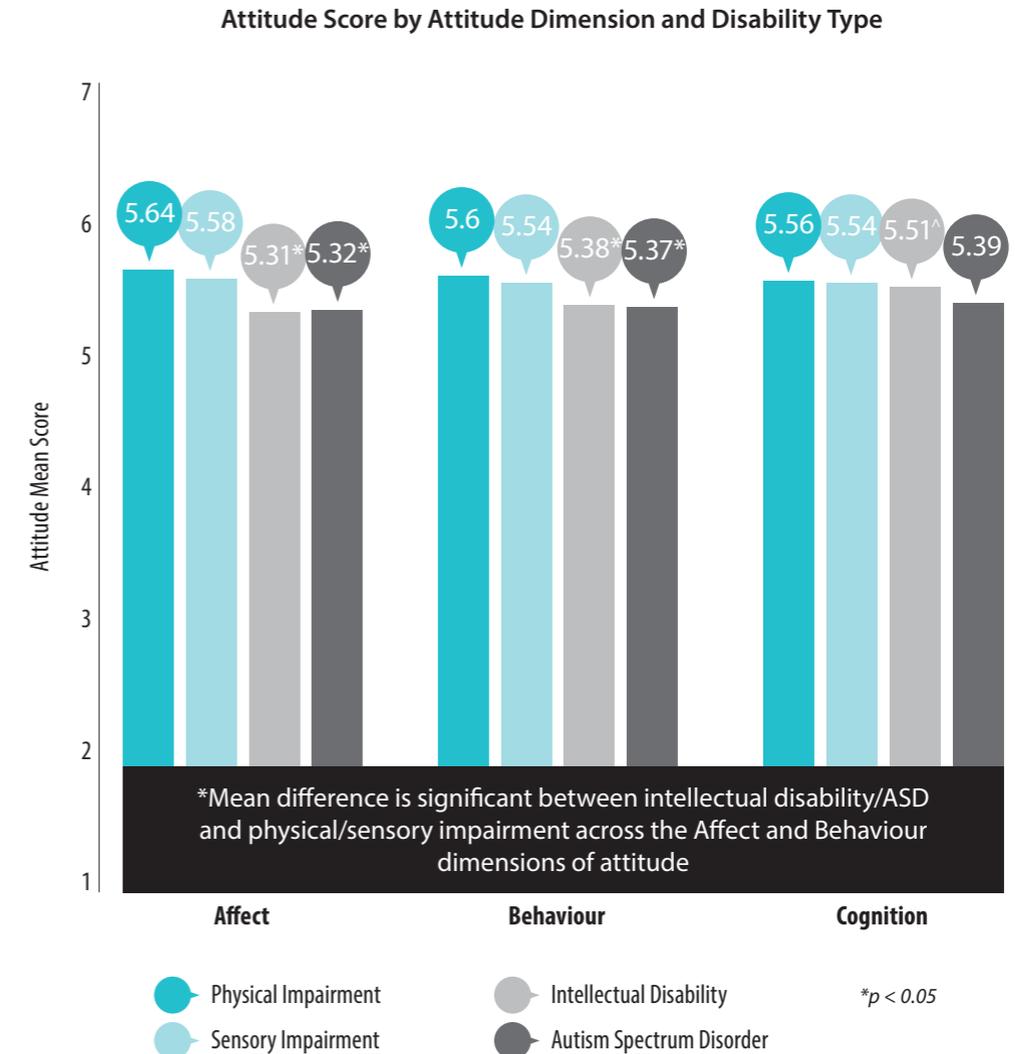
Despite being qualified, focus group participant **Steven** was turned down at a job interview upon disclosing his disability. Eventually, he obtained an IT support position. The 24-year-old hopes that employers can be more inclusive and open-minded towards persons with disabilities:

"...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]."

**Finding #3**

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.

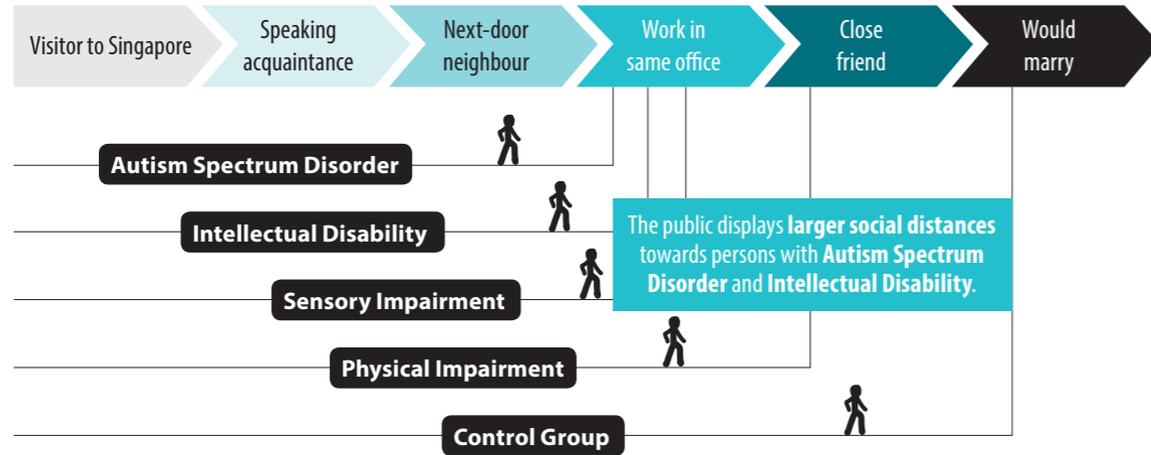
For example, people feel less comfortable sitting next to a person with Autism Spectrum Disorder on the bus compared to someone in a wheelchair. They would also tend not to offer assistance to someone who has an intellectual disability, as they would to someone who is deaf.



^ Mean difference between intellectual disability and Autism Spectrum Disorder is significant at p < 0.05 as well.

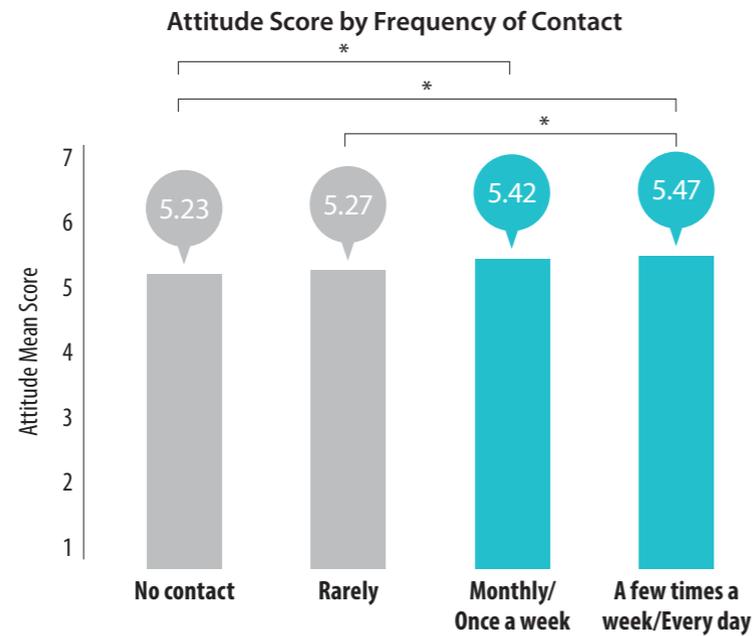
**Finding #4**

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 #5**

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



\*p < 0.05

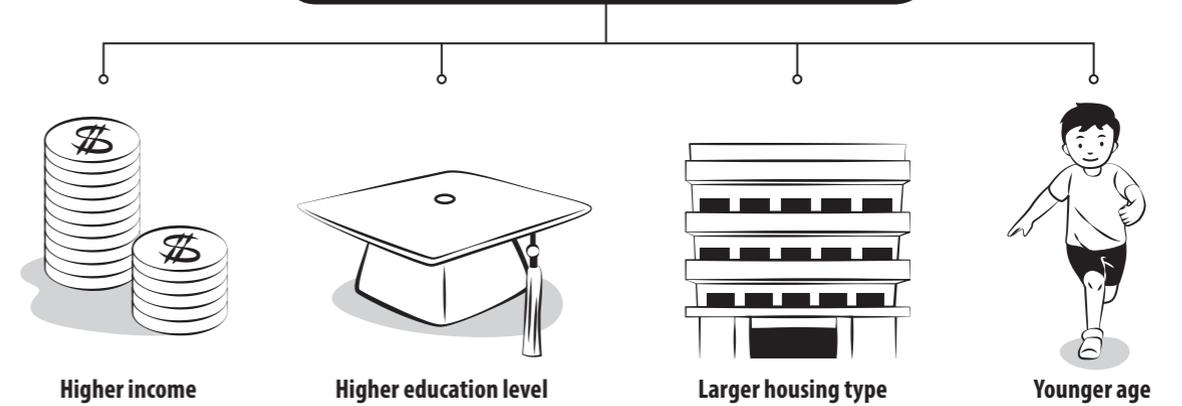


18-year-old Aditya was diagnosed with mild to moderate Autism Spectrum Disorder (ASD). As his mother and caregiver, focus group participant **Jaya** regards dignity to be more important than sympathy and empathy, and feels that it is important for people to develop a holistic understanding of persons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

**Finding #6**

**PUBLIC ATTITUDES WERE MORE POSITIVE FOR RESPONDENTS WHO HAD:**



## INSIGHTS AND IDEAS

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.

<sup>37</sup> 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<sup>38</sup> 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<sup>39</sup>. 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.

Finding #1

<sup>38</sup> According to the WHOQOL-DIS.  
<sup>39</sup> More information can be found on the NCSS website at <https://www.ncss.gov.sg/Press-Room/Publications/Detail-Page?id=Understanding-Persons-with-Disabilities>.

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.

“It’s just basic things...like just being more willing to give up their seats or asking us if we need help, that’s all...”

Focus group participant with physical impairment



Finding #6

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.

Finding #1

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.

Findings #7, #9

Efforts could be made to include persons with disabilities in activities such as sports, gatherings in the neighbourhood, volunteerism, 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.

Finding #5

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.

Finding #1

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.

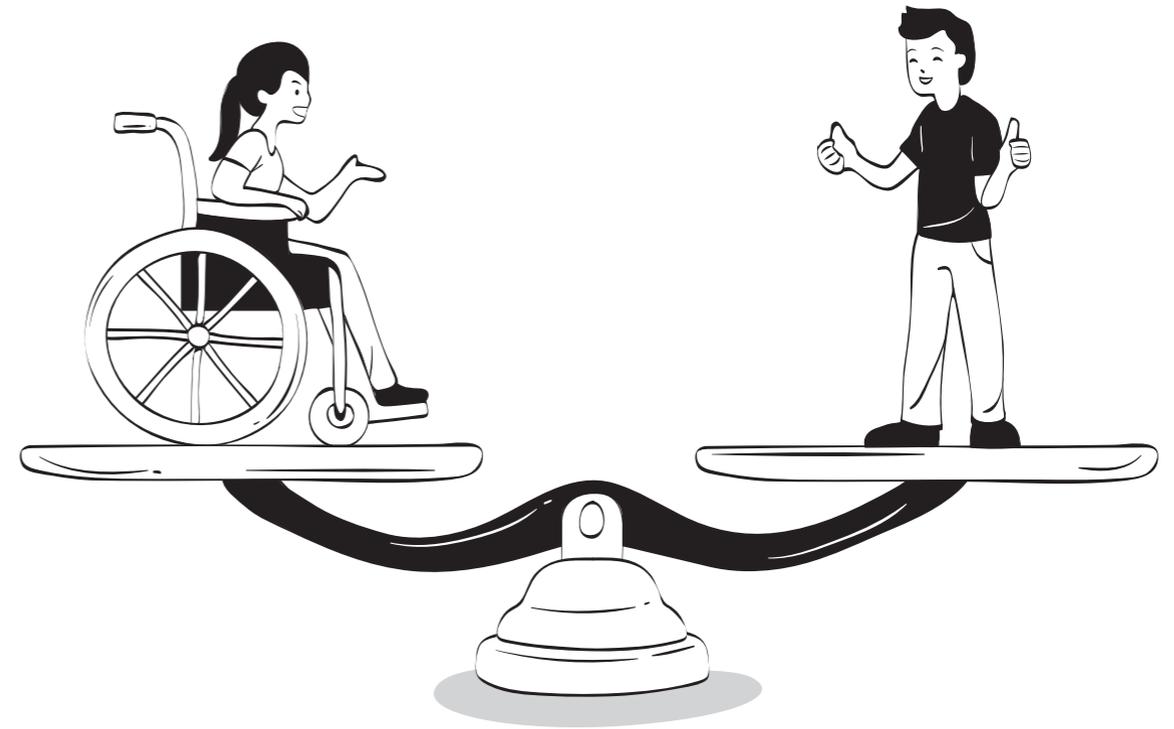
In the UK, the **Skillnet Group** is a social enterprise that supports persons with learning difficulties. It operates on a core ideology of *co-production*, which entails:

- 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.



“...everyone has equal responsibility to make that first move... to explain one’s condition... sometimes a lot is expected of disabled persons to always make the first move.”

Focus group participant with physical impairment

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.

## IDEA #2 Empower towards independence through availability and access to opportunities.

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.<sup>40</sup> 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.

Findings #3, #7, #9, #10

Persons with disabilities were more likely to have a lower quality of life if they did not have an income<sup>41</sup>. Conversely, those in open employment reported higher quality of life overall and in the domain of independence. Independence is also the top desired domain of improvement.

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.

Finding #4

Accessible workplaces improve independence.

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 know-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

Finding #10

Beyond issues of physical accessibility, persons with disabilities require skills to manage interpersonal relations effectively, be it with co-workers, supervisors or their clients.

Finding #2

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.

Finding #5

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<sup>42</sup>.

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.

<sup>40</sup> World Bank (2002). *A Framework for Empowerment: Summary*.

<sup>41</sup> Or allowance.

<sup>42</sup> 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<sup>43</sup>:

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

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.

Finding #3 #4

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

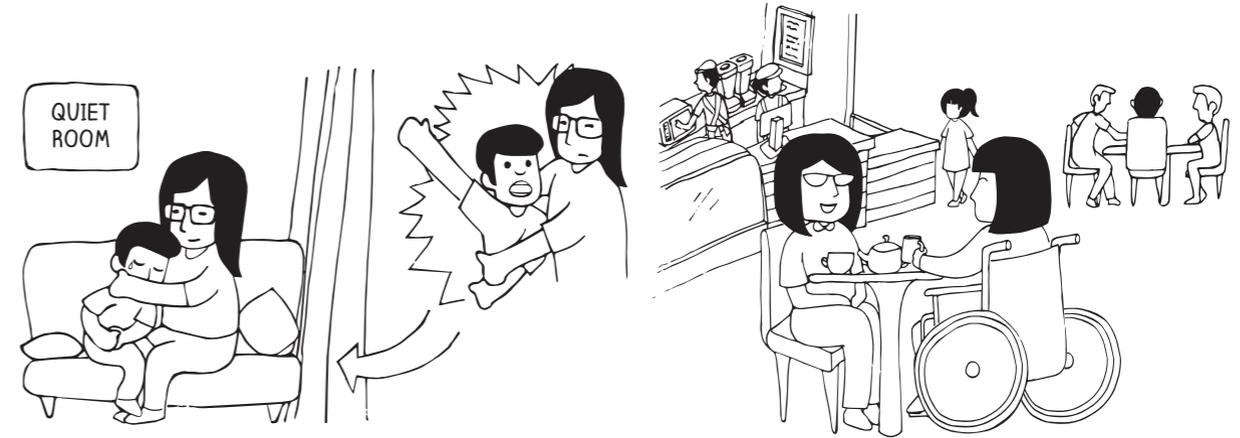
Again, it helps to ask people what they need. In Japan, **Fukuoka's subway system** has been lauded for its design which makes it highly accessible for persons with disabilities.

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.

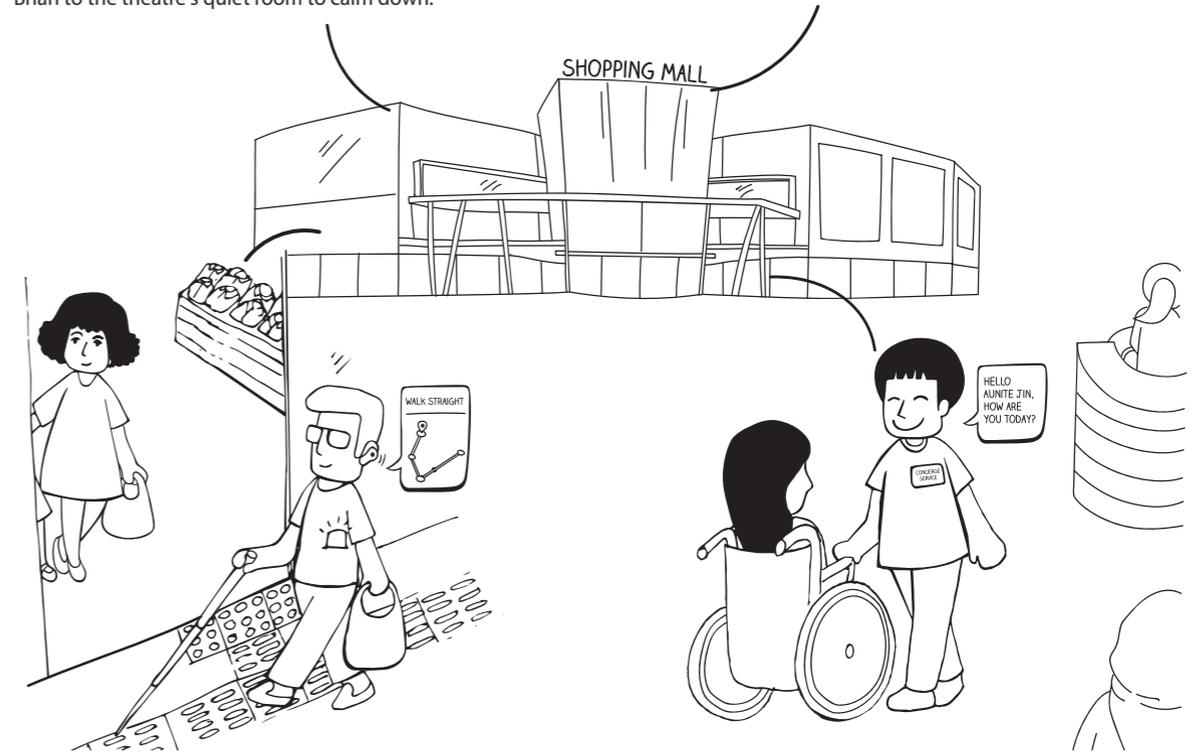
43 Danford & Tauke (2001). *Universal Design New York*.

The NCSS Pumpkin Lab also has some ideas of what an **inclusive mall** might look like:



Lynette brought her son with ASD, Brian, to the movie theatre at the inclusive mall. Brian had a meltdown and Lynette brought Brian to the theatre's quiet room to calm down.

Ginette, who has limited mobility, often meets up with her friends at the inclusive mall for afternoon tea and shopping.



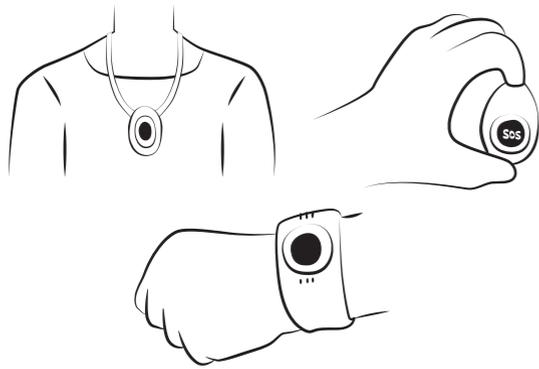
Kin, who is visually impaired, uses the inclusive mall's app to navigate around the mall when shopping. The app provides audible directions to guide Kin to his destination.

Aunte Jin, who has limited mobility and partial blindness, uses the mall's concierge service to get her shopping done. Students from nearby institutes of higher education volunteer for the concierge service.

Image: NCSS Pumpkin Lab

Finding #3

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<sup>44</sup>.



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](http://www.ncss.gov.sg/caregiving).

Finding #1

*Psychological support, adequate training and self-care* is important, given especially that many caregivers feel strained and burdened by the weight of their caregiving duties. The Enabling Masterplan 3 has advocated for a greater continuum of support in these areas, including training courses, counselling services as well as support and resource networks<sup>45</sup>.

Finding #6

Caregivers also related the importance of *temporary respite care options that could cater to emergency situations*. This was most apparent for caregivers of children with severe disabilities, those with chronic illnesses who required sudden medical appointments or hospitalisations or in the event of unforeseen circumstances. In this regard, neighbourhood disability services could be additionally equipped to handle such cases, or have emergency-ready staff who could operate on short notice.

In addition, *hospitals could be better equipped as key touch points*. In focus group discussions, caregivers of young children unanimously shared that the post-diagnostic phase was particularly distressing, having to struggle with accepting the diagnosed condition and finding sources of reliable help.

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 steady 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

Many prefer centre-based as opposed to home-based respite.

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.

<sup>44</sup> 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.

<sup>45</sup> The Enabling Masterplan 3 document can be found on NCSS' website at [https://www.ncss.gov.sg/NCSS/media/NCSS-Documents-and-Forms/EM3-Final\\_Report\\_20161219.pdf](https://www.ncss.gov.sg/NCSS/media/NCSS-Documents-and-Forms/EM3-Final_Report_20161219.pdf).

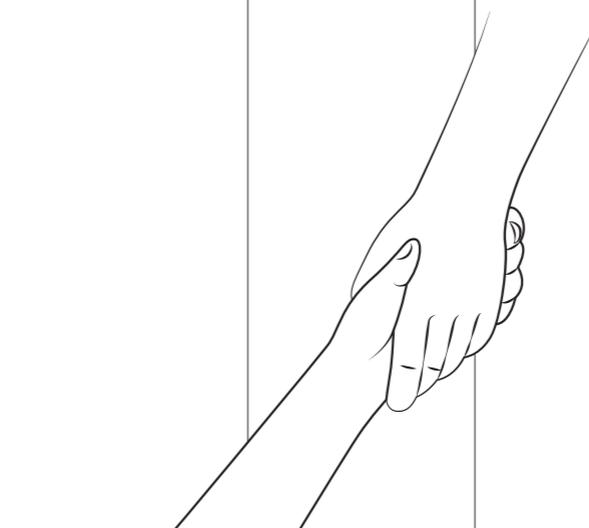
# THE DISABILITY SERVICE LANDSCAPE

The major social services which cater to persons with disabilities and their caregivers are tabled below<sup>46</sup>. For more information, a glossary is attached in **Annex B**.

		PERSONS WITH DISABILITIES		
		CHILDHOOD (0-6 YEARS)	YOUTH (7-18 YEARS)	ADULT (19 YEARS ONWARDS)
Severity of Disability	Mild	Learning Support-Development Support	<b>MAINSTREAM EDUCATION</b>	Vocational Education & Vocational Training
		Integrated Child Care Programme	Integration Support	Job Placement & Job Support
		Early Intervention Programme for Infants and Children	I. M. Powered*	Integration Support
			Learning Support	Sheltered Workshops
			<b>SPECIAL EDUCATION</b>	Drop-in Disability Programme
			Special Education Schools	Community Group Homes
			Special Student Care Centres	Adult Disability Hostels
			Buddy'IN*	Me Too! Club*
				Day Activity Centres
				Home-Based Care Services
			Children Disability Homes	Adult Disability Homes
			Inclusive Playgrounds & Children-in-Action*	
				Appropriate Adult Service*
			Social Service Office	
		Family Service Centre		
		Rehabilitation and Therapy Services		
		Arts Programmes (e.g. Very Special Arts Singapore)		
		Sports Programmes (e.g. Singapore Disability Sports Council)		
		Developmental Disability Registry		
		Emergency SMS Helpline Service		
		Assistive Technologies and Schemes (e.g. Assistive Technology Fund)		
		Transport Services, Subsidies and Schemes (e.g. Car Park Label Scheme)		

\* Indicates programmes in the pilot phase.  
<sup>46</sup> Services tabled are not exhaustive.

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



## 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:

IF YOU ARE A...	YOU CAN...
<b>PERSON WITH DISABILITY</b>	<p>Speak up, live life to the fullest, volunteer and participate in society.</p> <p>If you need help, visit <b>SG Enable's</b> 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.</p>
<b>EMPLOYER</b>	<p>Consider applying for benefits under the <b>Special Employment Credit</b> scheme, where the government pays a proportion of the wages of employees with disabilities. Seek out grants and initiatives such as the <b>Open Door Fund</b>, to find out more about support for hiring persons with disabilities in your organisation.</p> <p>Head over to SG Enable's <b>Disability Employment Portal</b> (<a href="http://employment.sgenable.sg">employment.sgenable.sg</a>) and explore the host of schemes and training programmes available.</p> <p>Help make the workplace more inclusive. Give persons with disabilities a chance, and ascertain their strengths instead of deciding their weaknesses.</p>
<b>SERVICE PROVIDER</b>	<p>Innovate. This need not be about the next big thing, but doing a little different with what's around you. For example, talking always helps – network and collaborate with others in the field.</p> <p>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.</p>
<b>GRASSROOTS WORKERS</b>	<p>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.</p> <p>Reach out to those in the neighbourhood with a disability, and ask what they need help with.</p>
<b>CO-WORKER/ FRIEND</b>	<p>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.</p> <p>Start a conversation with them, instead of about them, and talk about things openly.</p>
<b>CAREGIVER/ FAMILY</b>	<p>Don't be afraid to confide in others. If you need help, reach out to friends, family or other service providers.</p> <p>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.</p>
<b>MEMBER OF THE PUBLIC</b>	<p>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.</p> <p>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.</p> <p>Download a copy of the <b>Removing Barriers</b> series off NCSS' website and share it with people you know. Help others understand the challenges that persons with disabilities face, and encourage inclusive behaviour.</p> <p>To donate or volunteer for a disability-related cause, head over to <b>Giving.sg's</b> website (<a href="http://www.giving.sg">www.giving.sg</a>) to care deeply and share freely.</p>

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

## ACKNOWLEDGEMENTS

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NCSS	CONSULTANTS	PARTNERS
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## ANNEX A: GLOSSARY OF QUALITY OF LIFE DOMAINS AND FACETS

DOMAIN	FACET	DESCRIPTION
Physical	Pain and Discomfort	This facet explores unpleasant physical sensations experienced by a person and the extent to which these sensations are distressing and interfere with life.
	Energy and Fatigue	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.
	Sleep and Rest	This facet concerns how much sleep and rest, and problems in this area, affect the person's quality of life.
Level of Independence	Mobility	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.
	Activities of Daily Living	The facet explores a person's ability to perform usual daily living activities.
	Dependence on Medication or Treatments	This facet examines a person's dependence on medication or alternative medicines for supporting his or her physical and psychological well-being.
	Work Capacity	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.
Social Relationships	Personal Relationships	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.
	Social Support	This facet examines how much a person feels the commitment, approval, and availability of practical assistance from family and friends.
	Sexual Activity	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.
Environment	Opportunities to Acquire New Information and Skills	This facet examines a person's opportunity and desire to learn new skills, acquire new knowledge and feel in touch with what is going on.
	Recreation and Leisure	This facet explores a person's ability, opportunities and inclination to participate in leisure, pastimes and relaxation.
	Physical Environment	This facet examines the person's view of his/her environment. This includes the noise, pollution, climate and general aesthetic of the environment and whether this serves to improve or adversely affect quality of life.
	Transport	This facet examines the person's view of how available or easy it is to find and use transport services to get around.
	Safety and Security	This facet examines the person's sense of safety and security from physical harm.
	Home Environment	This facet examines the principal place where a person lives, and the way that this impacts on the person's life.
	Financial Adequacy	The 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.
	Health and Social Care	The facet examines the person's view of the health and social care in the near vicinity.

DOMAIN	FACET	DESCRIPTION
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.

## ANNEX B: GLOSSARY OF DISABILITY SERVICES

TERM	DESCRIPTION
Adult Disability Home	Provides long-term residential care for adults with disabilities who are neglected or whose caregivers are incapable of giving care. It aims to maximise the abilities of adults with disabilities through a host of recreational and training activities as well as the required therapies.  Short-time respite care can also be provided for those whose caregivers are temporarily unable to provide care for them.
Adult Disability Hostel	Offers long-term and short-term accommodation and residential-based training for adults with disabilities who are high functioning in their community living skills and do not require institutional care, but are unable to live with their families.
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.  Trained volunteers – termed Appropriate Adults – facilitate effective communications between PWIDs and the Police, to ensure that statements recorded are reliable.
Assistive 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.  Such technologies can also be used to help caregivers or social service organisations care better for their clients.
Buddy'IN*	A programme aimed at socially integrating graduating students from Special Education schools with their peers from Institutes of Higher Learning (IHLs) through semi-structured social activities and sessions.  Students with special needs practise age-appropriate social behaviours while their peers from IHLs gain awareness and understanding of persons with disabilities.
Caregivers Training Grant	A \$200 annual subsidy (per care recipient) that lets caregivers attend approved courses to better care for loved ones.  Eligible courses may be found on the Singapore Silver Pages website.
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.

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 55 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.  It also provides care respite for caregivers during the day.
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.  It also provides a slew of other benefits, including discounted rates for therapy services, assistive technology and access to some places of interest.
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.  It aims to keep participants meaningfully engaged and integrated within the community, while providing care respite for caregivers as well.
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/Levy 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).  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.
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.  For parents, the programme further engages them to discuss how they could better support their children's needs, as well as issues of caregivers' mental well-being.
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 stimulate 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.

TERM	DESCRIPTION
Integration Support	<p>A variety of programmes which aim to support persons with disabilities in daily life, and integrate them into mainstream activities and the community.</p> <p>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).</p>
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	<p>Offers employment and/or vocational training to adults with disabilities who do not possess the competencies or skills for open employment.</p> <p>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.</p>
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	<p>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.</p> <p>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.</p>
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	<p>Provides before/after-school care services for students aged 7 to 18 years old with special needs, and who attend mainstream or SPED schools.</p> <p><b>Integrated Student Care Centres</b> are mainstream student care centres catering to both mainstream students and students with mild to moderate social needs, while <b>Dedicated Student Care Centres</b> are located in SPED schools and cater only to students with special needs.</p>
Vocational Training/ Education	<p>Aims to provide accessible and targeted training and upskilling for persons with disabilities to be job-ready and stay relevant at the workplace.</p> <p>The <b>Enabling Academy</b>, for example, facilitates the development of curricula and customised programmes, and works alongside training providers to train employees with disabilities whenever possible.</p>

\* indicates programmes in the pilot phase.

Hotlines  
**SG Enable: 1800 858 5885**  
**MINDS Caregiver Support Services: 6547 8503**  
**Special Needs Trust Company: 6278 9598**

A more comprehensive list of helplines may be found on NCSS' website at <http://www.ncss.gov.sg/NCSS/media/NCSS-Documents-and-Forms/NCSS%20Internal%20Documents/List-Of-Helplines.pdf>

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# UNDERSTANDING THE QUALITY OF LIFE OF ADULTS WITH DISABILITIES



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

## Person-Centred

Individuals are capable of understanding, articulating and working through problems as well as making decisions on how to overcome them.

## 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, community and society at large.

Guided by these principles, NCSS conducted a series of studies to better understand the needs of persons with disabilities:

### STUDY ON PUBLIC ATTITUDES TOWARDS PERSONS WITH DISABILITIES

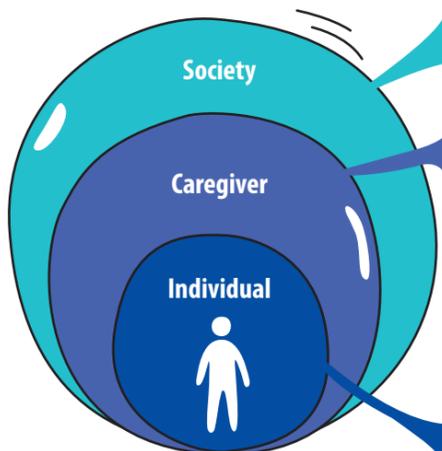
Public opinion was sought through the **Study on Public Attitudes towards Persons with Disabilities**, which uncovered how people feel, think, and would act towards persons with disabilities in various areas: Education, Employment and Public Access/Social Interaction.

### NEEDS ASSESSMENT ON RESPITE CARE FOR CAREGIVERS OF PERSONS WITH DISABILITIES

Looking at the state of caregivers, the **Needs Assessment on Respite Care for Caregivers of Persons with Disabilities** shed light on what their concerns were, how they regarded respite care as well as how they wished to be assisted in this arduous journey.

### QUALITY OF LIFE STUDY ON 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 LIFE STUDY ON PERSONS WITH DISABILITIES

- #1 Persons with disabilities experienced a lower quality of life than the general population, especially if they had *mental health issues* or *were aged 65 and above*.
- #2 Persons with disabilities scored low on *level of independence, feeling a sense of meaning in life* and in *social relationships*. While satisfied with their *physical environment* and ability to cope with *pain and discomfort*, they scored low on *financial adequacy* and in their abilities of *thinking, learning, memory and concentration*.
- #3 Persons with disabilities prioritised improvements in their *level of independence, psychological well-being* and in their *environmental resources*.
- #4 Those with intellectual disabilities and Autism Spectrum Disorder scored low on *feeling a sense of meaning in life, social relationships* and *psychological well-being*. Those with physical or sensory impairments scored low on *feeling a sense of meaning in life, level of independence* and *social relationships*.
- #5 Regardless of disability type, persons with *moderate-severe disabilities* experienced a lower quality of life than those with mild disabilities.
- #6 Persons with disabilities felt that they lacked *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.
- #7 Major Indicators of Lower Quality of Life:
  - Chronic disease
  - Lower functioning
  - No main daily activity (e.g. employment)
  - Not earning a personal income
  - No regular participation in sports or physical recreation
- #8 In holistically improving quality of life, 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* as well as increasing *social participation*.
- #9 Persons with disabilities who were *not engaged in a main daily activity* reported diminished *psychological well-being, social relationships* and a *sense of meaning in life*.
- #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.
- #11 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).

## NEEDS ASSESSMENT ON RESPITE CARE FOR CAREGIVERS OF PERSONS WITH DISABILITIES

- #1 Nearly *half* of caregivers of persons with disabilities experienced caregiver strain, with *4 in 10* being psychologically distressed. Many feel burdened by the weight of caregiving.
- #2 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
- #3 Profile of Caregiver Needing Respite Care
  - Has a chronic illness
  - Higher income or education
  - Employs a foreign domestic worker
- #4 Most caregivers were not aware of the term 'respite care'. Many narrowly linked it to babysitting or day care.
- #5 Caregivers regarded *child safety, service affordability*, as well as *having trained staff* as important in respite care services. They preferred *centre-based respite* as opposed to informal or home-based care.
- #6 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.

## STUDY ON PUBLIC ATTITUDES TOWARDS PERSONS WITH DISABILITIES

- #1 Attitudes towards persons with *intellectual disability or Autism Spectrum Disorder* were less favourable than those with physical or sensory impairment. Many persons with disabilities reported being treated differently in the form of misconceptions and preconceived judgements, over-protectiveness and differential treatment or pity.
- #2 Attitudes towards persons with disabilities were least favourable in the area of *employment*. Deeper probing suggests that the public perceives a person's disability as *inability to perform one's job*.
- #3 The public *feels and behaves more positively* to persons with *physical or sensory impairment*, than those with intellectual disability or Autism Spectrum Disorder.
- #4 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.
- #5 Attitudes towards persons with disabilities were better with higher frequency of contact.
- #6 Attitudes towards persons with disabilities were more positive if respondents had a:
  - Larger housing type
  - Higher income
  - Higher education level
  - Younger age



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

### 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**



### 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.

## Empower towards independence through greater and accessible opportunities.

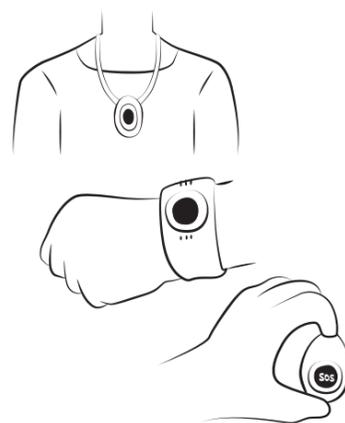


### Support persons with disabilities in their transition to the workplace.

- 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 etiquette training programmes for colleagues that debunk myths and stereotypes about disability, promote strengths-based approaches and impart effective communication strategies
- Be sensitive to incidents of discrimination

### 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:

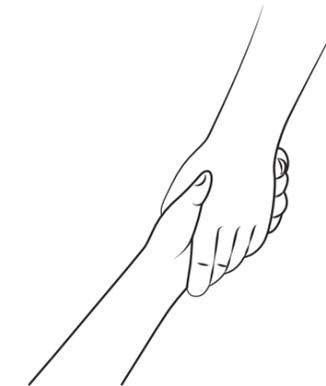
- A **ceiling hoist** that helps individuals move about more independently
- **Tinitell**, a wearable mobile phone that can read callers' names and the time out loud

## 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



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.

### 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

### 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 innovative options like **Jaga-Me** or **Match-A-Nurse** that match professional nurses to home users

