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People with Physical Disabilities in Singapore: Understanding Disabling Factors in Caregiving, Education, Employment and Finances

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Lien Centre for Social Innovation
SMU Change Lab

PEOPLE WITH PHYSICAL DISABILITIES IN SINGAPORE

**UNDERSTANDING DISABLING FACTORS
IN CAREGIVING, EDUCATION,
EMPLOYMENT AND FINANCES**



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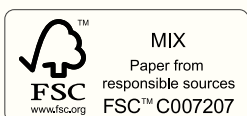
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SMU Change Lab

Over the years, the applied research conducted by the Lien Centre for Social Innovation (LCSI) has evolved into a community-engaged model. In 2014, SMU Change Lab was formed to support this model, with collaboration as its pivot. It is an action-oriented research and design programme within LCSI that investigates and responds to unmet social needs in Singapore. SMU Change Lab works with community members, voluntary welfare organisations and students to use qualitative primary research to collaboratively (re)design innovative responses to social needs. The objective is to suggest new or improved support mechanisms, services, practices or policies to meet the needs of the various vulnerable groups.

SMU Change Lab has tried various approaches to participatory action research by looking closely at three vulnerable communities in Singapore – the low-income elderly, persons with disabilities and single-parent families. The intent is to find practical applications from the research findings for issues that affect vulnerable communities.

The SMU Change Lab team consists of:

- Dr. Balambigai Balakrishnan, Research Associate
- Ms. Carol Candler, Consultant (*until Jan 2015*)
- Assoc. Prof. John Donaldson, Senior Research Fellow
- Dr. Emma Glendinning, Research Associate
- Ms. Mumtaz Binte Mohamed Kadir, Assistant Manager
- Ms. Sanushka Mudaliar, Senior Manager (*until Nov 2014*)
- Ms. Ranjana Raghunathan, Programme Manager
- Dr. Catherine Smith, Research Associate

Acknowledgements

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We would like to thank the following voluntary welfare organisations for their help in providing us access to participants: AWWA Teach Me Services, Bizlink, the Disabled People's Association, Muscular Dystrophy Association Singapore and SPD (formerly known as the Society for the Physically Disabled). We would also like to thank SG Enable and SPD for giving us feedback and insight through various stages of the project.

We thank the Change Lab team (as listed on page iv) for their support through the research process, the Lien Centre for Social Innovation's (LCSI) Director Jonathan Chang and LCSI staff, Jared Tham and Shirley Pong. We are also grateful to LCSI's Board for their support of Change Lab endeavours.

Further, we express special thanks to the undergraduate students of Singapore Management University, who conducted much of the fieldwork for this project, and particularly to Pearlyn Neo Hui Min, who was not only involved in the fieldwork, but also assisted with writing and analysis. We are also grateful to Opportunity Lab at Singapore University of Technology and Design for their support in the design phase of this research.

At the heart of this project are the contributions of the 100 participants who generously allowed us to see into their lives. They willingly shared their personal stories with us and we are indebted to them for their courage and honesty.

List of Abbreviations

ADL	Activities of Daily Living
CPF	Central Provident Fund
HDB	Housing and Development Board
IADL	Instrumental Activities of Daily Living
ITE	Institute of Technical Education
LCSI	Lien Centre for Social Innovation
MCYS	Ministry of Community Development, Youth and Sports
MOE	Ministry of Education
MSF	Ministry of Social and Family Development
MOM	Ministry of Manpower
MP	Member of Parliament
NCSS	National Council of Social Service
PWD	people with disabilities
SMU	Singapore Management University
SSO	Social Service Office
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VWO	voluntary welfare organisation

Executive Summary

As part of a research series on unmet social needs of vulnerable communities in Singapore, the Lien Centre for Social Innovation (LCSI) conducted a study on people with physical disabilities. This study explores the challenges that this community faces in various stages and spheres of life, and includes interviews with 100 respondents. The qualitative interviews sought to gain greater understanding of caregiving and caregivers, education, employment and finances. Where possible, we also investigated ways that these various components intersect with one another, as well as areas where the needs of people with disabilities intersect with challenges facing other vulnerable communities in Singapore, such as single-parent families, the elderly and foreign domestic workers.

CAREGIVING

Our findings demonstrate that much of the caregiving support for people with disabilities was offered within an informal network of care. That is, Singapore's policy of "family as first line of support" was quite visible in the caregiving practices of these families. Many of our respondents depended on other members of their households for support; particularly on immediate female family members. As many informal household caregivers were elderly, this seems to us to be a significant intersection of two vulnerable communities, and one which requires some long-term planning on the part of policy-makers. There is not only a possibility that the elderly will need more support, but many of them will represent a loss of the support network for people with disabilities, another vulnerable community, indicating that there will be even greater need for more support services.

Our study also revealed a lack of opportunity for respite among caregivers. Several of our respondents required significant levels of care – sometimes around the clock – and it was not always possible for their primary caregivers to find the opportunity to care for their own needs. Studies have indicated that it is critical that caregivers be given sufficient opportunity for respite, and our study demonstrates that this has not been possible for many caregivers of people with disabilities. This problem is further exacerbated in cases where there are multiple demands on a caregiver with few resources to address them adequately.

A more holistic system of support, and the provision of long-term care, would go much further towards addressing the challenges caused by a combination of intersections with other vulnerable communities such as foreign domestic workers, low-income elderly or single parents.

EDUCATION

The education system in Singapore poses unique challenges for people with disabilities. For example, not all schools are

sufficiently disabled-accessible, and respondents felt that their needs were not taken into account in the classroom. This placed them at a disadvantage with respect to their peers. Several respondents also shared accounts of being bullied at school, or at the very least experiencing isolation, contributing to challenges faced in completing their education. On the other hand, several respondents described experiences in which a special teacher, a support group of friends or a sibling in the same school enabled them to have a positive and successful educational experience.

Following their experience at school, many respondents had difficulties transitioning into employment. Job fairs were difficult for some to navigate in wheelchairs, or posed other accessibility challenges. In cases where respondents had benefited from some support at school, it was hard for them to transition into employment settings that were less accessible. In sum, our study suggests that there is much to be done to ensure that people with disabilities have access to schools that meet their needs, as well as equal opportunity to transition into employment following their education.

EMPLOYMENT

Seventy-five of our respondents are in some sort of employment, be it mainstream employment, or sheltered workshops; in the latter, they earn an income for performing different types of low-skilled tasks. Whether our respondents were employed in the open market, or received an income from sheltered workshops, their salaries tended to be quite low, and on their own could not provide for the needs of our respondents. This was particularly true for those with high healthcare costs or those who wished to live independently. Some respondents who were working in mainstream employment, or who had tried to do so, reported cases of discrimination. In some situations, they were not allowed any flexible arrangements to suit their unique circumstances; in others, respondents found it difficult to obtain employment, even when they met all qualifications. Finally, some of our respondents shared stories of having their contracts discontinued without any cause given.

Comments regarding job satisfaction suggested that each type of employment – mainstream employment and sheltered workshops – had positive and negative factors. While sheltered workshops took the needs of respondents into account, they often failed to provide opportunities to develop skills and to engage in interesting or satisfying work. On the other hand, mainstream employment, although it paid more and was often better matched to people's skill sets, often failed to provide the specific types of support that respondents required. Further, because it was so frequently difficult for people with disabilities to secure employment, our respondents occasionally accepted jobs that were ill-matched to their disabilities.

Some respondents offered stories of satisfaction in the workplace, which might help to shed light on what type of improvements would be welcome. For example, several felt that they benefited from having a supportive group of peers at work. Others appreciated having transportation provided, or having managers who made minor adjustments in the workplace to allow them to function at their best. Finally, some spoke of the importance of being challenged at work, and being able to use their imagination and creativity.

FINANCES

Given the low incomes that many of our respondents reported, it is not surprising that most had difficulties with their finances. The majority were not financially independent, and relied on family members to supplement their income from work. Medical expenses and the necessity to use taxis for transportation caused a significant strain on many respondents' finances. Although most respondents wished to save, few were able to do so. Several respondents who depend on family members for financial support worry about the future, when those family members will no longer be able to care for them. Further, many worry about their own deteriorating health, and the higher healthcare expenditures that will accompany this. While there are several services available to help with many of these issues, they are piecemeal, and do not serve to quell the worries of people whose futures pose various uncertainties.

HOUSING AND TRANSPORTATION

Low salaries, as well as a need for help with daily activities, meant that the majority of respondents stayed with parents. The percentage of home owners among our respondents is far lower than the Singapore norm. Many respondents worried about their living situation, especially when they shared poor relationships with others in the household, but continued to rely on them. Some of our respondents lived alone, due to lack of family support. Many of the living arrangements of the respondents were linked to dynamic and sometimes unstable caregiving relationships.

One of the factors that influenced the respondents' choices and experiences at work or at school was the availability of accessible and affordable transportation. Several rejected work opportunities because of poor transport facilities, and others faced similar limitations when they had to choose education options. Some of the challenges cited were that

buses were not disabled-friendly, long travel distance was physically strenuous and taxis were expensive. In addition, several respondents felt that the general public were not willing to give them space or seats.

SUPPORT SERVICES

Many respondents expressed worries about their future, especially with relation to their low salary and their overwhelming sense of insecurity about caregiving options. This was exacerbated in the case of respondents who depended on their parents for most of their daily living activities, housing, finances and healthcare support. As part of our interview process, we asked open-ended questions about the types of services that our respondents would like to see implemented. Many respondents expressed a desire for change or improvement in the support services; the following are some of their suggestions.

Support services

- Changes to the structure of service provision through less paperwork and bureaucracy
- Streamlining of support services, particularly for those who require multiple services
- Better publicity about the available services
- Services to be provided on the basis of individually tested means rather than family means
- Alternative approaches to caregiving, given that many participants could not afford to hire a domestic worker or a professional

Employment and finances

- Assistance in securing a job
- Higher wages
- Curbing discrimination in the workplace
- Improvement of sheltered employment
- Support with finances

Societal change

- Need for more disabled-friendly fitness centres and for those to be made more accessible
- Preventative health support and support for alternative healthcare
- Change in public perception about disability
- Better infrastructure including transportation as one respondent pointed out, "barrier-free and handicapped-friendly are different"

Part I

Introduction and Background to the Study

Section A: People with disabilities in Singapore

The Lien Centre for Social Innovation (LCSI), as part of a broad research plan to study and address unmet social needs in Singapore, has assessed the community landscape and identified six vulnerable communities in Singapore.¹ One such community is the disabled, whose various needs may not be sufficiently met by current social initiatives. This study concerns the challenges faced by those who are physically disabled and attempts to provide clarity on the nature of those challenges. They are not always related to the disability per se but are often caused and exacerbated by intersecting issues within the family and other structures in society at large.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) affirms that all people with disabilities are entitled to all human rights and fundamental freedom.² Singapore became a signatory of the convention in November 2012 and ratified it in August 2013 with reservations.³ Singapore implements the UNCRPD through the Enabling Masterplan, which sets goals and benchmarks for making Singapore a more inclusive society to better meet the needs of its disabled population. The most recent version of the Masterplan is dated 2012 - 2016, and its vision is to see "Singapore as an inclusive society where persons with disabilities are empowered and recognized, and given full opportunity to become integral and contributing members of society."⁴

Section B: Defining and estimating disabilities

Singapore has made some effort to define its understanding of people with disabilities (PWD), and to evolve that definition over time. In 2004, for example, then Ministry of Community Development, Youth and Sports (MCYS, now known as Ministry of Social and Family Development, or MSF) added the category of developmental disabilities to the 1988 definition written by the Advisory Council for the Disabled (ACD).⁵ Following this, the definition of PWDs in Singapore became, and remains, "those whose prospects of securing, retaining places and advancing in education and training institutions, employment and recreation as equal members of the community are substantially reduced as a result of physical, sensory, intellectual and developmental impairments."⁶ This definition, at its core, is based on a medical criterion, but also takes into account the socio-functional limitations in the environment and society. The latter part of the definition draws on the idea that society is in part responsible for the barriers facing PWDs, and that there is a great deal that society can and should do to reduce these.⁷

In 1987, the Central Registry of Disabled Persons shifted its purpose to become a register of users of disability services rather than an all-inclusive list register of PWDs;⁸ this register is now called the Developmental Disability Registry, and is managed by National Council of Social Service (NCSS).⁹ However, this approach does not take into account the number of people with disabilities who do not access government or NCSS funded services. In the absence of a registry, it is difficult to estimate the number of people with disabilities currently living in Singapore. Estimates based on 2010 data from the Health and Education ministries suggest that Singapore has around 97,200 people with disabilities; the majority – approximately 77,200 – are over the age of 18.¹⁰ The Enabling Masterplan 2012-2016 uses these estimates to suggest a prevalence rate of three per cent of the general population.¹¹ This prevalence rate takes into account acquired disabilities (defined in Section C on Research methodology) and PWDs who have not registered for services.¹²

1 Braema Mathi and Sharifah Mohamed, *Unmet Social Needs in Singapore – Singapore's Social Structures and Policies, and their Impact on Six Vulnerable Communities* (Singapore: Lien Centre for Social Innovation, October 2011).

2 "Convention on the Rights of Persons with Disabilities," <http://www.un.org/disabilities/convention/conventionfull.shtml>.

3 "Media Release: Singapore Ratifies UN Convention on the Rights of Persons with Disabilities (UNCRPD)," Ministry of Social and Family Development, <http://www.ncss.gov.sg/documents/uncrpd/docs/Media%20Release%20-%20UNCRPD%20ratification.pdf>.

4 "Enabling Masterplan 2012-2016," Ministry of Social and Family Development, <http://app.msf.gov.sg/Portals/0/Topic/Issues/EDGD/Enabling%20Masterplan%202012-2016%20Report%20%288%20Mar%29.pdf>.

5 See "Chapter 1: Definition of Disability and Prevalence Rate of Persons with Disabilities," in "Enabling Masterplan 2007-2011," Ministry of Social and Family Development, <http://app.msf.gov.sg/Research-Room/Research-Statistics/Enabling-Masterplan>.

6 Ibid.

7 Ibid.

8 Ibid.

9 "Developmental Disability Registry," National Council of Social Service, <https://www.ncss.gov.sg/VWOCorner/DDR.asp>.

10 Charissa Yong, "No Clear Data on Disability Situation in Singapore," *The Straits Time*, 13 March, 2014.

11 Enabling Masterplan 2012-2016.

12 Ibid.

Section C: Research methodology

OBJECTIVES

This study seeks to understand and examine the unmet social needs of people with physical disabilities in Singapore. In order that this research project be relevant to the Singapore context, we use this definition of physical disability derived from the Enabling Masterplan: “those whose prospects of securing, retaining places and advancing in education and training institutions, employment and recreation as equal members of the community are substantially reduced as a result of physical impairments.” The study does not include sensory, mental and intellectual impairments, in line with the definition.

INSTRUMENT

This research project used a single instrument to gather both quantitative and qualitative data: a questionnaire and a semi-structured interview that incorporated both open- and close-ended questions administered by an interviewing team. The questionnaire consisted of 43 main questions, each with follow-up questions. Each main section began with a broad question, which was designed to spark conversation. Ideally, the conversation would address many of the follow-up questions, and also provide valuable qualitative data. The following is an example taken from the research instrument.

Education - Can you tell me about your education and schooling life? If you have stopped studying, are you happy with the level of education you achieved?

(Prompt for an explanation of the answer – if yes, what is this happiness attributed to; if no, ask why not, what were/are the challenges faced? Is the respondent doing a course/ programme that he/she aspired to do?)

a) The subject’s type of school for primary and secondary:

- Special education school**
- Mainstream school**
- Mixed**

b) The subject’s highest level of education completed:

- No formal education**
- Primary**
- Secondary**
- ITE**
- Junior college**
- Polytechnic**
- University**

(If respondent attended ITE, poly and/or university)
Title of course(s): _____

Year of graduation: _____

Figure 1.1.: An excerpt from the questionnaire

Questionnaires were prepared in four languages: English, Mandarin, Malay and Tamil. English was the most commonly used language in this study. Eighty-four respondents communicated in English, followed by 10 respondents who communicated in Mandarin and six respondents who communicated in Malay.

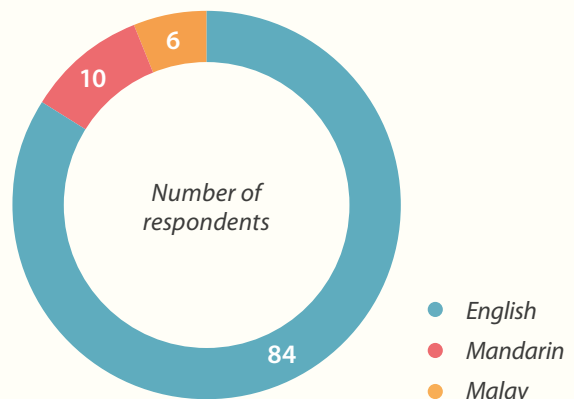


Figure 1.2: Languages used by the respondents

SAMPLING

The focus of this study was on people between the ages of 20 and 59, who live with physical disabilities. Participants were recruited through a combination of convenience sampling and snowball sampling. We approached voluntary welfare organisations (VWOs) to reach the people supported by their programmes. Some participants also referred us to other respondents. Through these methods we gathered 100 participants, who were either interviewed at the VWOs, in their homes or at convenient locations of their choice.

The team of interviewers, consisting of staff members from LCSi and students from Singapore Management University (SMU), were led by a Research Associate at LCSi. This project was directed by LCSi with the support of faculty from SMU. The research

team conducted face-to-face semi-structured interviews. A \$50 Fairprice voucher was given to each respondent as a token of appreciation for their participation.

SCOPE AND LIMITATIONS

The research has been limited to those who are aged between 20 and 59, since one of the aims of this study is to look at the needs of PWDs who are in the working age population. Further, we excluded those with severe disabilities who would not be able to participate in face-to-face interviews. We were also advised by VWO staff to limit the scope of the research to respondents who were mentally able to comprehend and participate in the interviews themselves, because there were several people with not only physical, but other accompanying disabilities. Further, to standardise responses and to limit variables, we decided not to interview caregivers as proxies.

Section D: Overview of respondents

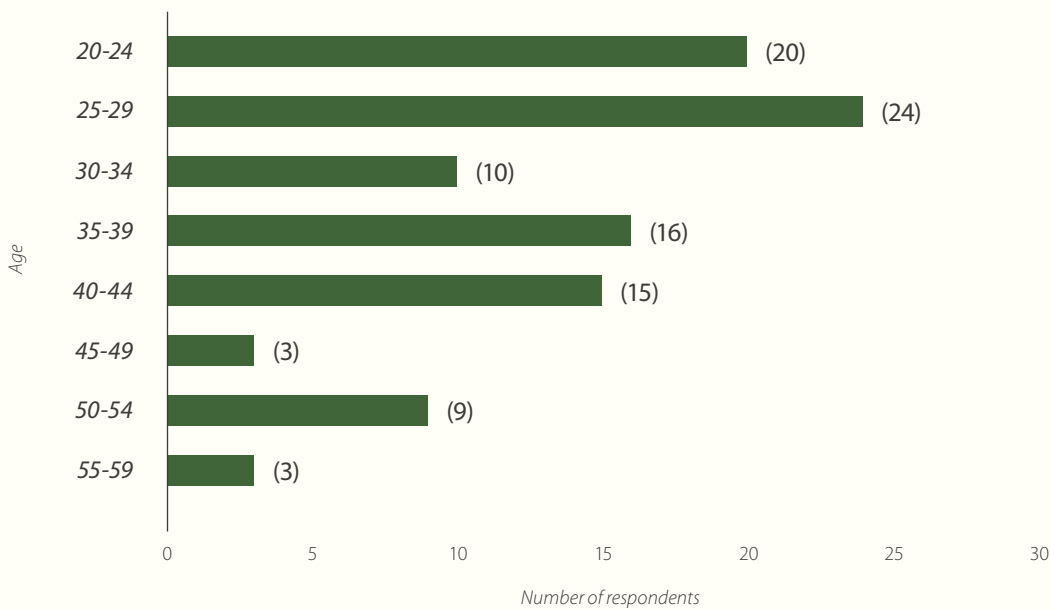


Figure 1.3: Respondents categorised by age

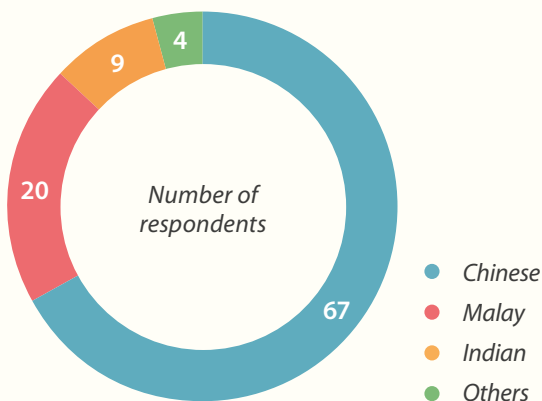


Figure 1.4: Respondents categorised by ethnicity

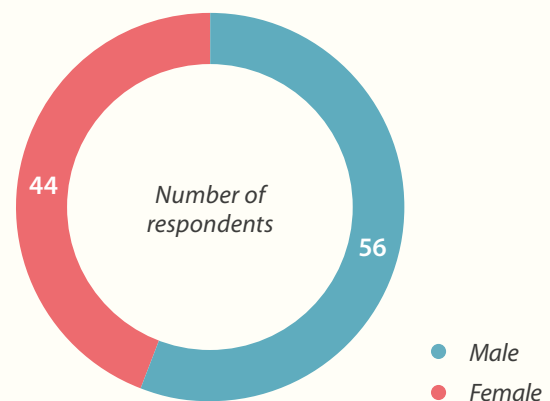


Figure 1.5: Respondents categorised by gender

AGE AT WHICH DISABILITY WAS ACQUIRED

We follow the Handicaps Welfare Association (HWA) in attributing two reasons for physical disability: “Congenital/hereditary: the person has physical disability since birth, or the disability developed at a later stage due to genetic problems, problems with muscle cells or injury during birth. Acquired: the person acquired the physical disability through road or industrial accidents, infections such as polio or diseases and

disorders such as stroke or cancer.”¹³

Forty-seven of our respondents reported having a disability as a result of congenital/hereditary issues, as shown in Figure 1.6.

For 55 of our respondents, the onset of the disability happened between the ages of 0 and 11; seven between the ages of 12 and 17; and 38 respondents experienced it after the age of 18. This is shown in Figure 1.7.

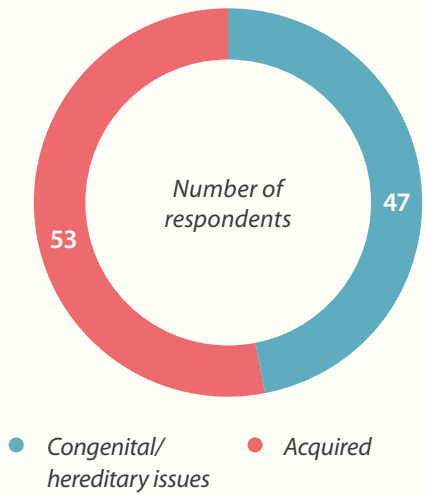


Figure 1.6: Reasons for physical disability

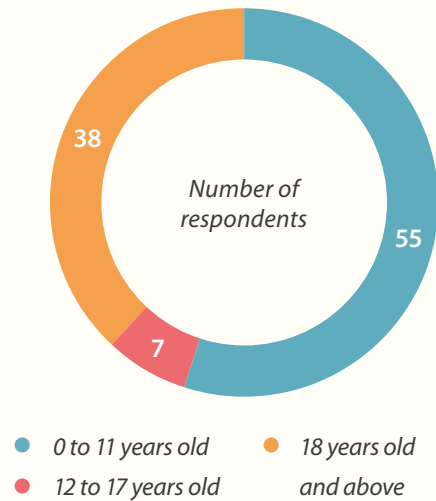


Figure 1.7: Ages at which physical disabilities were acquired

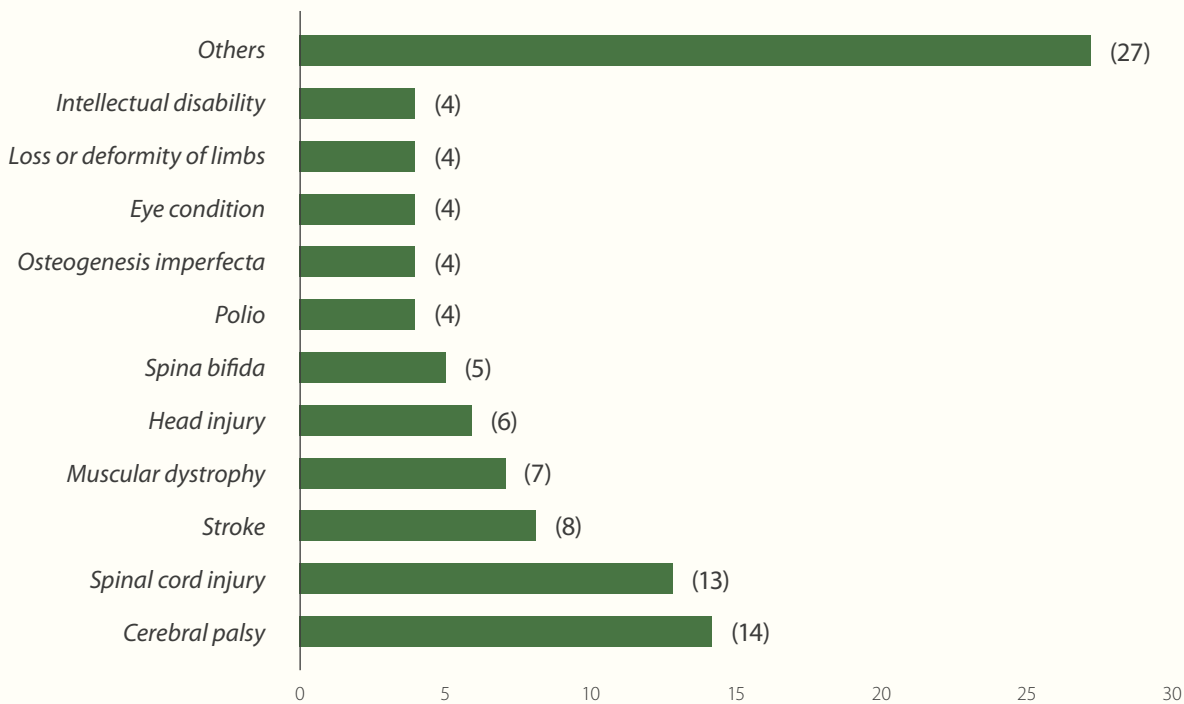


Figure 1.8: Number of respondents by categories of disabilities¹⁴

¹³ “General Information on Physical Disabilities,” Handicaps Welfare Association, <http://hwa.org.sg/news/general-information-on-physical-disabilities/>.

¹⁴ The 27 “Others” included here have physical disabilities that preclude them from engaging fully in many aspects of life, but whose disabilities are not found in sufficient quantities in this study to warrant separate categories. The chart also includes four respondents under ‘Intellectual disability.’ These respondents were included in the study because of their physical disabilities; while they happened also to have intellectual disabilities, these were not the focus of our research. As these respondents were able to comprehend and answer the questions in this questionnaire, they were recommended by VWOs.

Part II Analysis of Findings

Part II provides a close look at the findings of this study. As the research instrument (discussed in Part I, Section C) included both quantitative and qualitative questions, our analysis includes a mix of these types of data. In many sections, there are charts and graphs that offer specific figures which were the

result of the quantitative questions, and which contextualise the qualitative analysis that follows. The analysis in Part II pertains to caregiving, education, employment, finances, housing and support services, as well as the way that these concerns intersect with one another.

Section A: Extent of disabilities and daily activities

A major challenge facing people with disabilities, depending on the level and type of their disability, is carrying out activities that must be performed on a daily basis. “Activities of Daily Living” (ADL) and “Instrumental Activities of Daily Living” (IADL) are the two broad categories of self-care and daily tasks investigated, IADL involving tasks which are somewhat more challenging. The ADL and IADL are generally used in assessing the type and level of care that PWDs require, and whether they need aids or a caregiver.¹⁵

Table 2.1 below shows the numbers of participants who need help with specific IADL activities. Many more respondents had

difficulty standing for two hours or lifting an object weighing approximately 10 kg, than walking a distance of 200 to 300 meters or climbing 10 steps without resting. Further, most of our respondents tended to have poorer lower body strength or challenges with mobility, which explains why 94 were able to endure sitting for long hours but unable to do other activities. They used mobility aids such as crutches, walking frames and wheelchairs, motorised or otherwise. The questions about ADL and IADL activities are usually used by professionals to gauge and classify disability, whereas we used some of them in the questionnaire to understand what types of care might be needed, and where gaps might exist.





	 Yes, on my own	 Yes, with help	 Unable to do on my own	 Type of mechanical aid used
Walk 200 to 300 meters	49	16	35	Crutches, rollers, walking frames, motorised wheelchairs
Walk within the house	64	7	29	
Climb 10 steps without resting	51	10	39	
Stand (go without sitting) for two hours	38	8	54	
Continue to sit for two hours	94	4	2	
Stoop or bend their knees	56	11	33	
Raise their hands above their heads	80	5	15	Use one hand or depend on human support
Grasp with fingers or move fingers easily	69	11	20	
Lift an object weighing approximately 10 kg	42	10	48	

Table 2.1: Number of respondents who needed help with IADL activities

15 See, for example, Shirley A. Morris, Sylvia Sherwood and John N. Morris, “A Dynamic Model for Explaining Changes in Use of IADL/ADL Care in the Community,” *Journal of Health and Social Behavior* 37, no. 1 (1996): 91-103.

As for ADL tasks (Table 2.2), more than two thirds of the respondents were able to perform the activities on their own. Nineteen respondents needed help in standing up from a chair or sitting on a chair, and 18 respondents needed help with

dressings or undressings. Respondents also mentioned a variety of other challenges, such as buttoning a shirt, tying hair and so on. Table 2.3 demonstrates the type of disability which led to the most need for assistance with various daily activities.




	 Yes, on my own	 Yes, with help	 Unable to do on my own
Take a bath/shower	85	10	5
Dress/undress	82	12	6
Eat	97	3	-
Stand up from a bed/sit down on a chair	82	7	11
Clear bowels	85	6	9
Clear bladder	86	5	9
Use the sitting toilet	77	8	15

Table 2.2: Number of respondents who needed help with ADL

	0 to 1	2 to 3	4 to 5	6 to 7	8 and above	Total
Cerebral palsy	4	5	1	-	4	14
Spinal cord injury	1	-	1	1	10	13
Muscular dystrophy	1	-	1	1	4	7
Stroke	2	3	2	1	-	8
Head injury	1	2	3	-	-	6
Spina bifida	-	1	2	2	-	5
Osteogenesis imperfecta	1	-	1	2	-	4
Loss or deformity of limbs	1	1	1	-	1	4
Intellectual disability	3	1	-	-	-	4
Polio	-	-	3	1	-	4
Eye condition	1	3	-	-	-	4
Others (Please specify)	7	11	5	1	3	27
	22	27	20	7	24	100

Table 2.3: Number of ADL and IADL that respondents needed help with by type of disability

About half of our respondents needed help performing four or more ADL and IADL activities. Those with cerebral palsy, spinal cord injuries and muscular dystrophy reported needing the most help. Of the 13 who had spinal cord

injuries, 12 had some form of paralysis, either from the chest down or from the waist down, and three respondents mentioned having complete paralysis with slim chances of improving over time.

OTHER ACTIVITIES

In addition to ADL and IADL activities, respondents were asked whether they were able to perform other household activities such as preparing their own meals, taking care of financial matters

and using the phone. These household activities contribute to independent living, and difficulty with them indicates areas where people with disabilities require assistance. When our respondents were unable to perform these activities (more details in table 2.4), they were assisted by those living with them.




	 Yes, on my own	 Yes, with help	 No, need help/ Not applicable
<i>Prepare own meals</i>	63	3	34
<i>Take care of financial matters such as paying utilities (electricity/water)</i>	73	7	20
<i>Use the phone</i>	96	3	1
<i>Dust, clean up and do housework</i>	69	4	27
<i>Take public transport</i>	74	12	14
<i>Do laundry</i>	64	3	33
<i>Manage medication/injections</i>	78	3	19

Table 2.4: Number of respondents who needed help with household activities

Out of the activities above (Table 2.4), the respondents reported needing the most help with housework, preparing meals and doing laundry. With respect to preparing meals, respondents reported that they faced difficulty carrying heavy things, starting a fire on the stovetop (which requires two hands) and reaching for things, if

they were confined to wheelchairs. Doing laundry appeared to be difficult largely because of the challenge of hanging clothes to dry on bamboo poles. Like ADL and IADL, these are activities that must be performed on a reasonably consistent basis, and which many cannot manage without assistance from caregivers.

Section B: Caregiving and caregivers

While some challenges can be addressed with the help of aids, others require help from caregivers. Caregivers to our respondents included various people, such as nuclear family, other relatives, friends, domestic workers and VWOs. While not everyone needed a caregiver for their ADL or IADL activities, having people to assist with these tasks reduced the burden on the respondents, especially from the necessities of preparing meals, doing laundry and maintaining the house.

CARE FROM HOUSEHOLD MEMBERS

Singapore relies on the family as “first line of support” approach

to caring.¹⁶ Consequently, family members are expected to juggle their own livelihoods with responsibilities of caring for their disabled relative. This means that people with disabilities are often at the mercy of the vagaries of family relationships: the size of the family, the abilities of family members, the financial situation and the time available to the family members.

The Figure 2.1 shows that at least 90 respondents lived with others in their households. Seventy-four respondents lived with their parents, and in some of these cases, other family members lived there as well. Seven respondents were married and lived with their spouses and children, if they had any.

16 See, for example, “ComCare and Social Support Division,” Ministry of Social & Family Development, <http://app.msf.gov.sg/About-MSF/Our-People/Divisions-at-MSF/Social-Development-and-Support/ComCare-and-Social-Support-Division>.

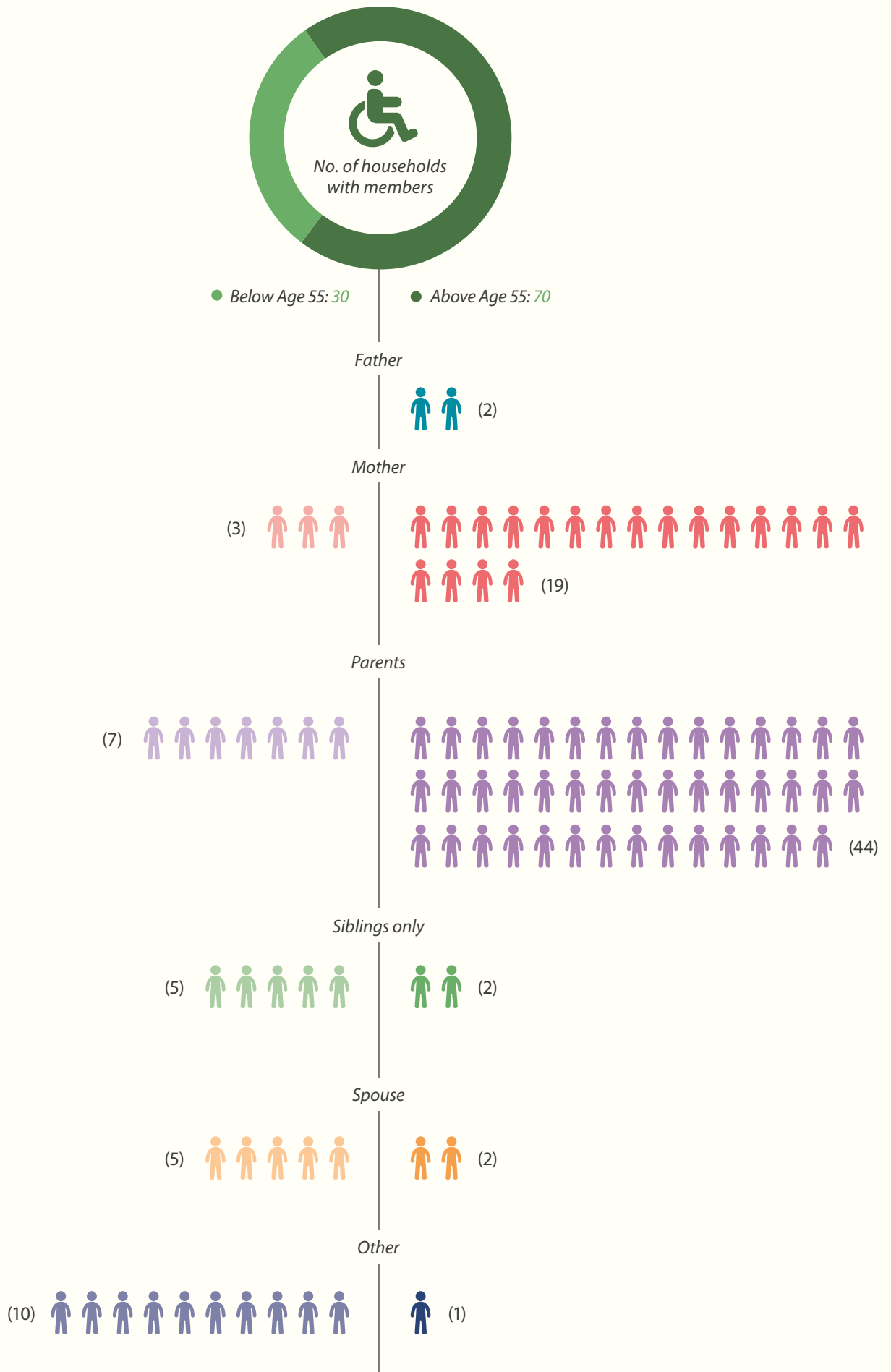


Figure 2.1: Household members staying with PWDs

INTERSECTION OF PWD NEEDS WITH ELDERLY NEEDS

Seventy of our respondents had a household member who was 55 years and above. While 55 is by no means an age where people are considered elderly, it is the age when people are allowed to withdraw from their Central Provident Fund (CPF) account to plan for retirement. As many of these older people provided some household assistance to our respondents, it is worth looking at how they plan care for their disabled children in their old age. Singapore's population is ageing rapidly; the total number of elderly is expected to reach 900,000 by 2030.¹⁷ With this trend in mind, the government continues to put in place more programmes to assist the ageing population, such as the Pioneer Generation Package and the Silver Support Scheme.¹⁸ However, the needs of this population do not exist in a vacuum, particularly if many of these older Singaporeans are providing caregiving assistance to people with disabilities. Some respondents expressed concern about who would support them after their parents were no longer able to do so.

The situation is particularly worrying when the primary caregivers already have serious health challenges themselves. For example, both parents of Respondent16 have health-related concerns. Her mother is recovering from a stroke, has weak legs, diabetes and high cholesterol; her father has cancer, which has caused him to quit his job as a security guard. This family not only faces caregiving concerns, but also financial worries due to the loss of an income. In

the case of Respondent7, his mother, who is his primary caregiver, recently had a fall and broke her leg. Additionally, his father has dementia. In such cases, it is clear that a system which is relying on ageing parents to give support to people with disabilities is not sustainable in the long term.

In some cases, it is possible to see the caregiving transitions as parents grow more infirm, or face other health problems, and are no longer able to care for their disabled children. For example, Respondent24 has been living in a nursing home for around three years; because her father had a stroke and her mother suffers from mental illness, there is no longer anyone to provide care for her. In another case, Respondent32's caregiving situation has had to change, because her mother suffered a stroke, and must also continue to care for the respondent's grandmother. Her sister now provides most of her care and emotional support.

The direction of the caregiving is also occasionally reversed, with the disabled person becoming responsible for caring for elderly parents. For example, Respondent7, who is 42 years old, acts as a caregiver to his ageing parents. Similarly, Respondent51 had been caring for his mother, who died in 2011 after suffering from mental illness. Respondent70 lives independently, and has an elderly father in a nursing home, who asks him for financial help frequently. There were instances where ageing parents had to care for their adult children with disabilities, and their elderly parents and/or grandchildren as well.



Respondent #7

He is a 42-year-old man, who has been in a wheelchair since the age of 15. He has had several surgeries before that, and was able to walk during his early childhood. He lives with his ageing parents who have medical issues. His father has dementia and his mother recently had a fall and fractured her legs. At the time of the interview, she was still in the hospital and the respondent would visit her every day. His mother was his primary caregiver, and used to support him with more than half his ADL and IADL activities prior to her fall. Mother would cook for all in the family, but with her in the hospital, they have been relying on food stalls for meals. "Sometimes, when there is no money, there is no food to eat," he says. Respondent also cares for his father in the night. Respondent has been working in a sheltered programme for more than 10 years, and worries about "what will happen to me after my parents?"

Many respondents had caregiving responsibilities of their own, often for ageing parents. Caregiving roles in respondents' households were many and varied, and they often shifted as health concerns changed, family members entered different

stages of life, and the landscapes of individual lives shifted. Informal caregiving networks such as these can elevate stress levels, as the vagaries of life might at any point disrupt caregiving relationships, and leave people with significant unmet needs.

17 "Our Demographic Challenges and What These Mean to Us," National Population and Talent Division, <http://www.population.sg/key-challenges/#.VRtdeUakre0>.

18 "Home," Pioneer Generation Package, <https://www.pioneers.sg/en-sg/Pages/Home.aspx>; "Budget 2015," Ministry of Finance, http://www.singaporebudget.gov.sg/budget_2015/pe.aspx#s3.

GENDERED ASPECT OF CAREGIVING

Among those who had only one parent as a household member, 22 respondents lived with their mothers and two lived with their fathers. In addition to women being highly represented in the households, mothers were the primary caregivers to 25 of 43 male and female respondents who needed active care. The rest were also supported primarily by women who were relatives, such as sisters and aunts, or foreign domestic workers. Women performed most of the caregiving roles, especially when the

tasks involved intensive support for daily living activities such as bathing, feeding, helping with toileting, etc. In contrast, the typical ways that brothers or fathers supported respondents were through housing, financial support, providing assistance for their transport, or helping out with household chores. Generally, all caregiving tasks that involved intensive support to the respondents in their daily activities (ADL and IADL) were performed by women, especially mothers. Additionally, mothers also provided other forms of care such as housing, food, transport, financial and emotional support.



Respondent #62

She is a 37-year-old woman who became dependent on others when she had a stroke one year ago, which resulted in paralysis on her right side. She had a stroke in her sleep; her mother found her unconscious, called an ambulance and took her to the hospital. She spent a month in the hospital, the first five days being in ICU. The prognosis indicated that she may never be able to walk and would have to be tube-fed. She exercises with her mother, who is a housewife, every morning, climbing stairs and stretching. Her father supports her financially. Her mother cooks for her and takes her to exercise/therapy and her brother, who lives with his nuclear family, helps out by taking her to acupuncture sessions. She co-owns the house that she lives in with her parents. One year on, she is now able to walk and only needs assistance with activities that involve her right hand. She attributes her successful recovery to all her family members and cheerfully concludes by saying, "Mum is good, father is good, brother is good, but mother is [the best]!"

In many of the respondents' descriptions of their mothers' caregiving efforts, it is clear that these women rarely rest and are responsible for most aspects of their child's life. For example, Respondent6 reports that her mother rarely takes a break, as she is always with her. The mother has high blood pressure, and receives no support from anyone else. Respondent10's mother trains him to walk and takes him to therapy. She manages his finances, such as his bank account and ATM card; she worries that he might overspend, as the respondent suffers from memory loss as a result of the accident that led to his disability. His mother rarely gets to rest, because she also looks after her grandchildren. When these women experience sudden health concerns of their own, the household quickly feels the impact, as in the case of Respondent7 on page 9.

In some cases, mothers occasionally do manage to get some respite from caregiving work, as in the case of Respondent14, whose mother goes for a religious retreat for five hours every week. Respondent40's mother, who had to leave her job to be a caregiver when the respondent was born, gets to go out when the respondent leaves the house. In the case of Respondent50,

his wife is the primary caregiver and breadwinner after the respondent had an accident; she occasionally gets a break when her elderly parents help with household chores and provide transport for the respondent. In instances where a domestic worker is the main caregiver, the mother would take on her roles on days when the worker is unavailable.

This dramatic difference in numbers of mothers versus fathers providing support to people with disabilities could also signal problems in the future. Women often spend some part of their lives, if not all of it, outside of the formal workforce because of caregiving responsibilities and therefore frequently face challenges when they approach retirement age.¹⁹ In Singapore, many women at retirement age rely on children and other family members to assist them financially. Even so, many of these women struggle to keep up with the rising cost of living in Singapore and their rising healthcare costs. The government has rolled out various schemes to help with these costs in recent years, and has signalled its interest in continuing this trend. It should be noted that women will reach their elderly years with not only themselves to care for, but a household member who

19 See especially Gosta Esping-Anderson, "A New Gender Contract," in *Why We Need a New Welfare State*, Gosta Esping-Andersen, ed. Duncan Gallie, Anton Hemerijck and John Myles, (Oxford: Oxford University Press, 2002); Gertrude Schaffner Goldberg, *Poor Women in Rich Countries: The Feminization of Poverty Over the Life Course*, (Oxford: Oxford University Press, 2010).

also needs their physical and financial support. In such cases, these elderly women will not only face the problems they would likely have inevitably encountered, but will have added issues involving the isolation and loneliness that can accompany this kind of caregiving.²⁰

INTERSECTIONS WITH SINGLE PARENTHOOD

In addition to the overlapping needs of the elderly and PWDs,

and women and PWDs, single parenthood is another factor impinging on the needs of a disabled person. Twenty-four respondents lived with single parents, either as a consequence of divorce, separation or widowhood. Like the other intersections, these sets of circumstances exacerbated the stresses in the family. This was particularly true when it came to finances. Single parenthood also meant that there were fewer human resources in the household to assist in caregiving for the person with disabilities.



Respondent #58

He is a 27-year-old man who comes from a single-parent family. He lives with his mother, younger brother and younger sister. They lived in a rental flat previously and waited two years to purchase the house they currently live in, jointly owned by the respondent and his mother. The respondent has had cerebral palsy since birth, which affects all four of his limbs. He has minimum finger control and needs assistance with almost every task he undertakes. His mother works two jobs to support the family – one in the day and the other, the night shift; his siblings provide him with most of the caregiving support, such as taking turns to drive him around and help him fulfil basic needs such as showering. He reported knowing that taking care of him as a disabled person is very taxing and frustrating for everyone, especially his siblings, as he feels that they do not have enough time for their studies or private lives because of him. Hence, they recently hired a foreign domestic worker to help reduce the caregiving demands on his siblings.

SIBLING SUPPORT

Those who had no parents, or whose parents were in aged care homes, often lived with their siblings. In the case of four respondents, this living arrangement involved the sibling's spouse and children as well. In other cases, siblings have taken on the task of caring for their

ageing parents, as in the cases of Respondent41 and Respondent42. This assistance from siblings eases the respondents' challenge of having to care for themselves as well as their ageing parents. In cases where siblings were not providing much support, it was usually due to their commitments to their own families, to being in school or to them already caring for their parents.



Respondent #99

She is a 32-year-old woman who has had muscular dystrophy since birth. She finds it hard to hold things and relies on a wheelchair to get around. After her parents passed away, she inherited their house and now lives with her younger brother, who is also her main caregiver. Her older brother moved out after marriage, but visits her every weekend. They both help her with transport, finances and buying food. Her sister-in-law cooks for her when they visit her during the weekends. Her younger brother also provides her with emotional support and help in performing daily activities. She reported that her brother pays for almost everything. He has his own job while she spends six hours a day, three days a week at a day care centre. Her brother, the main caregiver, gets respite over the weekends when he goes out with his friends.

20 Alfred P. Fengler and Nancy Goodrich, "Wives of Elderly Disabled Men: The Hidden Patients," *The Gerontologist* 19, no. 2 (1979): 175-183.



Respondent #83

He is a 52-year-old man who had a stroke 12 years ago and subsequently epilepsy after the stroke. He comes from a large family and is currently living with his younger brother and the brother's family, whom he relies on most for caregiving support. He spends more time talking with his sister-in-law, who helps with cooking and maintaining the house, and meets his brother every night upon his return from work. He reports having helpful neighbours whom he can call on for help when he falls or if he needs to open a can of food. As his brother has a family of his own, the respondent does not want to trouble them too much. He therefore joined a sheltered work programme a few months ago, which allows him to contribute to paying the utility bills with his salary (\$100 per month). He rarely leaves the house for leisure activities, as he does not want to trouble his siblings.

DOMESTIC WORKERS

When domestic workers were the primary caregivers, they, like mothers, managed their caregiving roles alongside several other responsibilities. It was often the case that domestic workers were not exclusively employed to assist the disabled person; in this study, 16 households employed a domestic worker, and in 15 of these households, the domestic worker also took care of others – sometimes elderly parents or young children – in the household. In 11 of the 16 households, the disabled person needed intensive care for more than eight ADL and IADL activities.

While mothers who acted as caregivers were often supported by other family members or domestic workers, domestic workers themselves rarely enjoyed any respite from the daily grind of intensive work. Some would get only a single day off in a month, after having completed some tasks in the morning of the same day. Respondent90 describes his experience with his domestic worker: “In the morning, she carries me to bathroom, gives me bath, will help me into the shirts on the bed. Then if I need to go to the toilet, she carries me to the toilet, and then I go back to the bed to put on my trousers. She carries me to the wheelchair if she has to go out, if not she puts me in my ‘office’ - I spend a lot of time on the chair, watching shows, playing online games with friends. She is healthy and carries me at least five times a day. The helper only goes out once a month, she will ask if she needs to go out.”



The helper only goes out once a month, she will ask if she needs to go out.”

Respondent93 shares a similar experience, “[Domestic worker] has been working for three years. She doesn’t always go on her off-days; if she has to go, then she settles me in the morning and goes off for a few hours.”

In many cases, the domestic workers do all the caregiving tasks for the disabled people, including accompanying them everywhere. In addition to those responsibilities, domestic workers also perform other household chores such as cleaning, cooking and generally maintaining the household. Respondent63 relied on her domestic worker to get through her university education as she needed help to move around, get food and meet other basic needs.

Not all families can afford domestic workers, of course. While Ministry of Manpower (MOM) does not publish the specific income requirements, they acknowledge that income is taken into account, and must be sufficient to cover not only salary, but food, housing and all the other costs that come with employing a domestic worker.²¹ While some subsidies are available on levies for foreign domestic workers, the remaining cost is still more than many low-income families can afford.²² Further, those with diseases such as Alzheimer’s, dementia or any other condition that might interfere with one’s ability to understand and manage the working relationship, are barred from employing foreign domestic workers.²³

21 “What is the Minimum Income Needed to Employ an FDW,” Ministry of Manpower, <http://www.mom.gov.sg/faq/work-permit-for-fdw-faq/what-is-the-minimum-income-needed-to-employ-an-fdw>.

22 “Frequently Asked Questions (FAQs) on Enhanced Foreign Domestic Worker (FDW) Levy Concessions 2015,” Ministry of Manpower, <http://www.mom.gov.sg/~media/mom/documents/budget2015/faqs-on-enhanced-fdw-levy-concession.pdf>.

23 “Employer Requirements for Hiring an FDW,” Ministry of Manpower, <http://www.mom.gov.sg/passes-and-permits/work-permit-for-foreign-domestic-worker/eligibility-and-requirements/employer-requirements>.



Respondent #80

He is a 22-year-old man, who is currently pursuing undergraduate studies in a local university. When we asked about his family, he lists his father, mother and brother and continues, “Can I call my helper a relative? She has been with us since my mother got pregnant, until now, for 22 years. Even for my study trips, I take her along as she helps with my daily activities.” The respondent has cerebral palsy, which makes him unable to walk, and he lacks control in his hands. He depends on his domestic worker for bathing, dressing, transferring (for example moving from bed to chair) and cleaning after bowel movements. He has relied on her since birth and feels her absence the most when she leaves for her hometown on two weeks’ leave every year. When she is away, “my parents struggle to carry me or transfer me between chair and bed. [Are there] any tools to help me? [Are there] no support services such as part-time nurses? I will probably have to move out to a nursing home in the future, [without such assistance].”

Given the cost and eligibility requirements, it was often the case that domestic workers were only hired when the caregiving and household responsibilities became too much of a burden for the family to handle on their own. In the case of Respondent 98, his mother was the main caregiver; the domestic worker was hired after the mother developed severe back pain from frequently carrying him and helping in basic daily needs. In this case, there is some concern that the domestic worker will also end up being overburdened, as she is responsible for caring for the respondent and also his mother, on top of performing household tasks.

The above cases provide some insight into the life of a domestic worker caring for a person with disabilities in Singapore. Although a law was passed in 2013 indicating that domestic workers must have one full day per week as a “day off,” when the work permit was issued or renewed after 1 January 2013, it is clear that this is not happening in many situations where they are caring for households with many needs.²⁴ It is possible that the family and the foreign domestic worker have agreed to one day’s salary in lieu of each day off, which is within MOM guidelines, but it was not clear whether or not this was the case in some of the families we met.²⁵

The situations of the domestic workers described above indicate the need for respite to caregivers. More and more attention has been paid in recent years to making sure that full-time caregivers are not overtaxed, are able to get time off to see to their own needs and to recover from the stress and exhaustion

that comes from providing around-the-clock care. Various organisations in Singapore have acknowledged these needs: For example, a “survey on informal caregiving,” conducted for MSF, known at the time as MCYS, found that caregivers were at risk of depression and high levels of stress, among other health concerns, and recommended both respite services and support groups.²⁶ Further, the resource guide for caregivers, produced by the Agency for Integrated Care, reminds caregivers of the importance of rest and of maintaining their own health and wellbeing.²⁷

SUPPORT PROVIDED BY FAMILY AND FRIENDS OUTSIDE HOUSEHOLD

A limited number of respondents received help from family members or friends who were living outside their household unit. The majority of these respondents had fewer ADL/IADL caregiving needs, and were therefore able to live independently. We found that caregiving support provided by non-household members was performed more frequently by friends than by family members (see Section F on housing and domestic arrangements).

CHALLENGES RELATED TO CAREGIVING EXPERIENCES (TO CAREGIVERS AND PWDS)

The families that experience the most challenges in caregiving are those in which the disabled person has a degenerative condition, in which case the caregiving needs continue to grow over time, as he or she becomes increasingly dependent

24 “Rest Days and Well-being for Foreign Domestic Worker,” Ministry of Manpower, <http://www.mom.gov.sg/passes-and-permits/work-permit-for-foreign-domestic-worker/employers-guide/rest-days-and-well-being>.

25 Ibid.

26 Angeliq Chan et. al., *The Survey on Informal Caregiving: Summary Report* (Singapore: Ministry of Community Development, Youth and Sports, 2010). <http://app.msf.gov.sg/Portals/0/Informal%20Caregiver%20Survey%20Summary%20Report%20%28upload%29.pdf>.

27 “Caregiver Basics 101: A Resource Guide for New Caregivers,” (Singapore: Agency for Integrated Care (AIC) and Centre for Enabled Living (CEL), March 2012), http://www.aic.sg/uploadedFiles/AIC_CEL_40pp_FD.pdf.

on others for help with more and more activities. The situation was especially challenging when they hired domestic workers to handle their caregiving needs. Respondent98 describes how his domestic worker did not have any training, and often seemed to not know what to do. They eventually had to hire another domestic worker. However, other kinds of challenges were faced by the respondents and their caregivers.

Some of our respondents were aware of the effort that family members and others had to make in order to care for them. This awareness occasionally led them to feeling like a burden to their families. Two respondents who live alone have no social network and are reluctant to “trouble anyone” when they need assistance. Respondents who live with siblings and their families also feel some anxiety about not wanting to rely on their families, especially when the family members have children. Respondent39 lives with his mother. His father has died and he reports feeling like a burden to his mother and his brother. He has attempted suicide, feeling that there is no point in living.

The lack of health insurance for people with disabilities is also

a major cause of worry and anxiety, especially when their conditions are likely to worsen over time. A respondent uses her entire monthly salary to buy insurance and depends on her parents for all day-to-day expenses. It is also not always clear to respondents that their insurance is limited.

Many respondents expressed a desire to learn to be more independent and be able to perform their daily activities, to earn enough to be self-sufficient and to be active and pursue their interests. Feeling a high level of dependence on family members is difficult for many respondents, especially in situations where they do not enjoy a close relationship (see Section F on housing and domestic arrangements). As the situation stands, staying with family may actually have negative financial repercussions; staying with their siblings’ families disqualified some respondents from getting certain types and levels of state support due to the household income criteria of means-tested programmes. For example, the Programmes for Persons with Disabilities offers a base subsidy of \$300, followed by subsidies “of up to 75 per cent” for households whose incomes are \$1500 or below.²⁸

Section C: Education

Our respondents faced unique challenges in the education system, from experiencing bullying, having difficulties with transportation, to having parts of their education interrupted due to an incident related to their disability, and so on. This section seeks to provide nuance to the understanding of the areas in which Singapore’s education system might be improved to better meet the needs of people with disabilities.

All respondents in this study have been part of an education system which was not compulsory for them. In Singapore, the education of children with “special needs” has not been included in the Compulsory Education Act.²⁹ The Enabling Masterplan addresses this issue, and calls for the Ministry of Education (MOE) to make the education for special children compulsory by 2016. The Masterplan also proposes extending the graduation age of those who are in the special education system from 18 to 21 years old.

As shown in Figure 2.2 below, 51 respondents are either pursuing or have completed tertiary education. No relationship was found between education level and the age at which the disability occurred. There was also no correlation between education level and ethnicity or sex. The only significant factor we found was age: The younger respondents in this study seemed to be more likely to have a higher qualification than the older ones. There are several possible reasons for this. We note that the education system has become more inclusive and accessible compared to several decades ago. Further, younger individuals today are more likely to pursue tertiary education than in the past several years.³⁰ Additionally, our sample recruitment may have influenced the pattern, as most older respondents were recruited through VWOs running sheltered workshops, and younger participants were recruited by VWOs providing education support system for students with disabilities.

28 “Example of Government Schemes, Eligibility Criteria, Assistance Quantum & Number of Beneficiaries,” Ministry of Social and Family Development, [http://app.msf.gov.sg/Portals/0/Table%20of%20Government%20schemes%20and%20eligibility%20criteria%20\(PQ\)%20final.pdf](http://app.msf.gov.sg/Portals/0/Table%20of%20Government%20schemes%20and%20eligibility%20criteria%20(PQ)%20final.pdf).

29 This is the language used both in the Compulsory Education Act and in the Enabling Masterplan on this topic.

30 “Education Statistics Digest 2014,” Ministry of Education, 2014, <http://www.moe.gov.sg/education/education-statistics-digest/files/esd-2014.pdf>

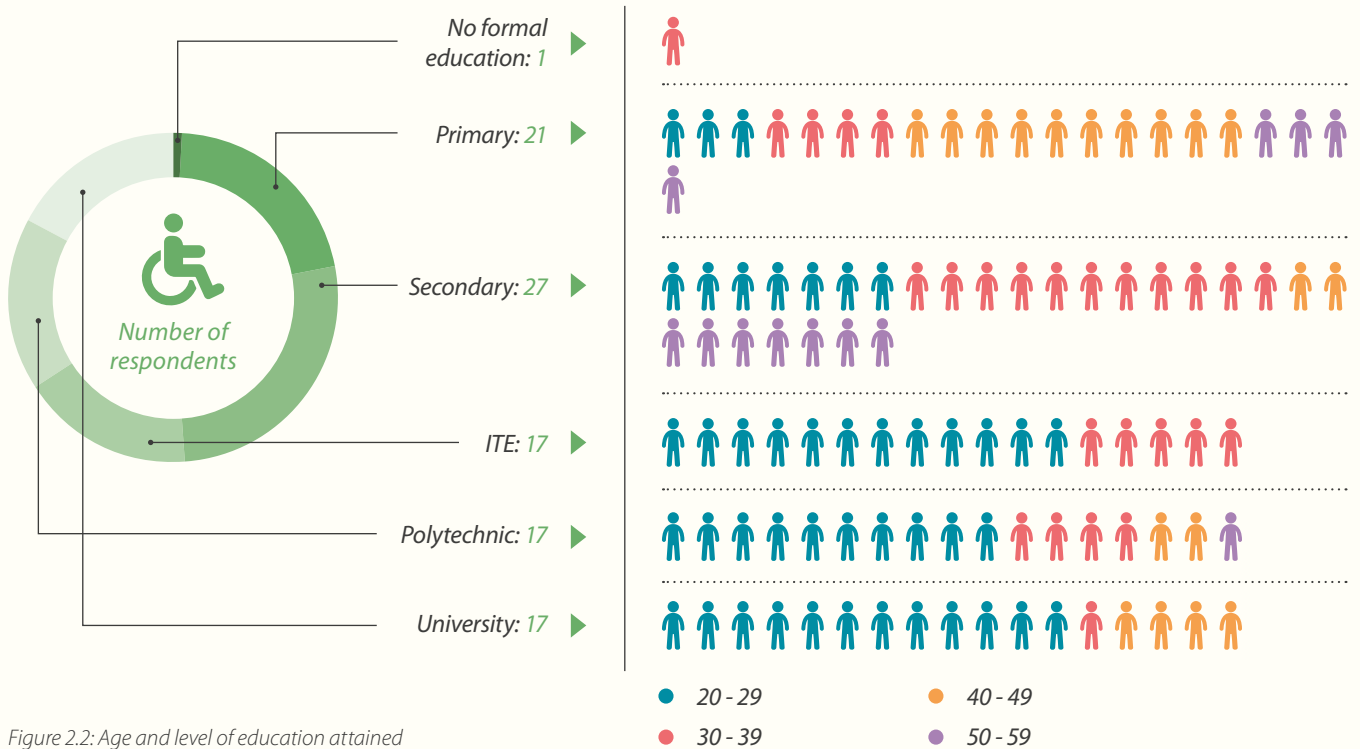


Figure 2.2: Age and level of education attained

EFFECTS OF THE ONSET OF DISABILITY ON EDUCATION

The majority of our respondents had a disability between the ages 0 to 11, before commencing formal education. Figure 2.3 is a breakdown of the levels of education attained by them.

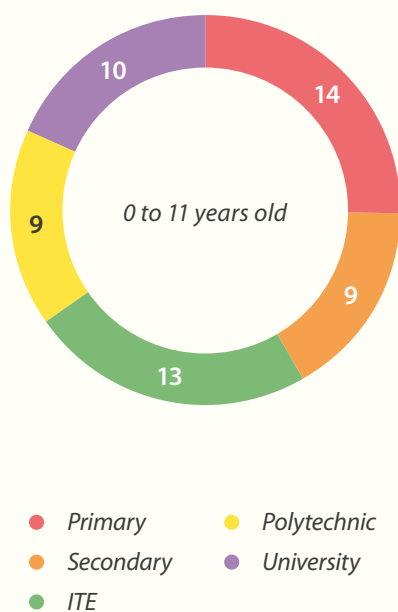


Figure 2.3: Levels of education attained by people whose disability was established prior to 11 years of age.

Fifteen respondents acquired their disability during the course of their education; among them, six were able to complete their education in spite of this, while nine had to discontinue studying due to their disability. In other cases, an accident caused health-related concerns, which precluded these respondents from continuing with their education. For example, Respondent85 developed a high fever which left him bedridden; this fever continues to affect him to date. Respondent76 developed cancer and had to undergo chemotherapy for three years. Respondent55 was in a coma while enrolled at university.

The respondents who discontinued studying due to the onset of a disability or health issue, cited various reasons for doing so. In cases where respondents had conditions that worsened with time, they could not continue because of their deteriorating health and the stress it placed on them. Specifically, they offered reasons such as physical tiredness, unsuitable hours at their school and travel inaccessibility. Many respondents who came from poor families had to work in order to support their families and themselves financially, and they left their studies in order to be financially independent. For example, Respondent26 said, "Education costs money, but I need money, so I focus on working." Similarly, Respondent39 started working at a young age because he had to support his mother, who was abused by his alcoholic father. Some others felt compelled to leave school because they were not able to cope in the competitive system, or because they had taken too long to complete the various levels of education. For example, Respondent7 reached the maximum age limit allowed for

completion of the secondary school examination, and had to leave school without having completed his education.

CHALLENGES FACED DURING THE EDUCATIONAL PROCESS

Many respondents felt that their disabilities were not sufficiently taken into account with respect to the unique challenges they faced. Respondent12, who studied through distance education, requested for an extension on deadlines, but local representatives of his overseas university did not agree. He asked the overseas university directly and his request was granted. Respondent44 felt that he had to put in more effort, as his memory was not as good as that of his peers, and it was challenging for him to write his notes quickly. He also had to speak louder during presentations, which he found challenging. Some conditions affected the respondents' ability to join in activities after school, which in turn affected their social life, meaning that they had to put in more effort to make friends. This also had implications for their scholarship opportunities, as many scholarships demand high levels of extracurricular activities and experience in leadership roles.

Accessibility in schools was also an issue for many respondents. One had to transfer from one school to another in order to use lifts and accessible toilets. Respondent32 had to be carried by her teacher to class, because the school was not wheelchair-friendly. Respondent57 had trouble with heavy doors in his school. Respondent80 was in schools which had no lifts, and so all classes had to be held downstairs. Respondent21, on the other hand, was in wheelchair-friendly schools, but his transition to university was a challenge because of detours necessary to access the school via wheelchair ramps, making the distances longer.

BULLYING

Several respondents spoke about being bullied at school as one of their challenges, without being specific about the details. In fact, some respondents seemed to experience it as "normal," or had come to expect it at schools and to feel pleasantly surprised when there was an absence of bullying. Respondent12 reported being bullied throughout primary and secondary school. Respondent23 said, "Other students disturbed me a bit, but I have learnt to get past that," appearing almost resigned to the inevitability of school bullying. Similarly, Respondent81 rationalises her bullying experience in secondary school by saying "maybe they are quite young, so they do it."

Oftentimes, students with disabilities were not able to find

an escape from their bullying. Respondent14 was bullied during secondary school, and complained to the headmaster, but that caused the students to retaliate and bully him more. Respondent8 remarked that "The teachers scold them [the bullies], but not that much. Teachers can't do much because they get attacked too." In one case, a student who was assigned to help the person with a disability was actually the problem: Respondent40's student-helper used to bully her into doing things faster. Respondent40 went on to say that "fortunately everyone else was nice."

// **The teachers scold them [the bullies], but not that much. Teachers can't do much because they get attacked too."**

In addition to experiencing bullying, many respondents spoke of a general sense of isolation and loneliness. Respondent65 reported being bullied during secondary school, and added that it felt all the worse because he had no friends. Respondent91 did not experience any explicit bullying, but he found it difficult to make friends, which made his studying experience more challenging. Respondent3's friends found out about her disability and stopped talking to her; her lack of friends in the polytechnic made the completion of the course challenging.

TRANSITION TO EMPLOYMENT

Many respondents faced challenges with their transition from education to employment. For example, Respondent90 had difficulties finding an internship, because he needed constant care from his domestic worker but he was not allowed to bring her to help him. According to MOM's "employment rules for foreign domestic workers," it is only legal to ask a domestic worker to perform tasks outside her place of residence if she is caring for a child or an elderly person; there is no mention of a disabled person. Further, the penalty for breaking this rule is fine of up to \$10,000.³¹ Respondent11 had been in wheelchair-friendly schools, but the transition to employment was difficult for him because the companies that offered him jobs were not wheelchair-friendly. Two respondents cited challenges with job fairs: they were not wheelchair accessible, they were overcrowded and difficult to navigate.

31 "Employment Rules for Foreign Domestic Workers," Ministry of Manpower, <http://www.mom.gov.sg/passes-and-permits/work-permit-for-foreign-domestic-worker/employers-guide/employment-rules>.



Respondent #81

She is a 22-year-old woman who is currently doing a diploma course in a local polytechnic. She has had congenital disorder since birth which causes her to get tired easily; she is unable to walk and has slurred speech. "If I am tired, then I go home and sleep; my body does not function properly," she says. She is mobile and requires minimal help with her ADL and IADL needs. Her only worry is about finding a suitable job once she finishes her higher education. "If I get tired, I cannot work, I need to rest. Working life is long hours; will they [the employers] understand?"

POSITIVE EXPERIENCES OF SCHOOLING

Despite the challenges faced by many people with disabilities, there were several who had had a positive experience during their schooling years. Going to school, mingling with other students and being in a learning environment allowed respondents to meet others and mix with a diverse group of people. The presence of friends, relatives and helpful teachers played a major role in contributing to such positive experiences. For example, Respondent45 had an older brother in the same school; he protected him and ensured that he was not bullied. Further, some teachers made efforts to support some of the respondents by printing large font notes, giving extra time to complete examinations and partnering them with other friends for extra support. Some teachers also helped to find the students internship opportunities.

Some respondents felt that they started enjoying school life only after secondary levels, either in the Institute of Technical Education (ITE) or a polytechnic because there they were treated like "normal" people and felt included. When Respondent21 started at university, the administrative staff took him around and introduced him to the campus. Friends also helped him around in wheelchair when needed. Respondent96 recounts times when her university professors would meet her in the canteen, or some other convenient location. She grinned as she explained that she graduated without ever having to enter her department building. While it is admirable that her professors took personal interest to help her overcome the environmental barriers, these individual efforts are no substitute for structural changes that would render them less necessary.

Section D: Employment

Of our respondents, 25 are in mainstream employment, 10 of whom are in part-time jobs. The majority of our working respondents (46) are in sheltered employment, which are

operated by VWOs. Four participants have other sources of income. Twenty-five respondents are unemployed.

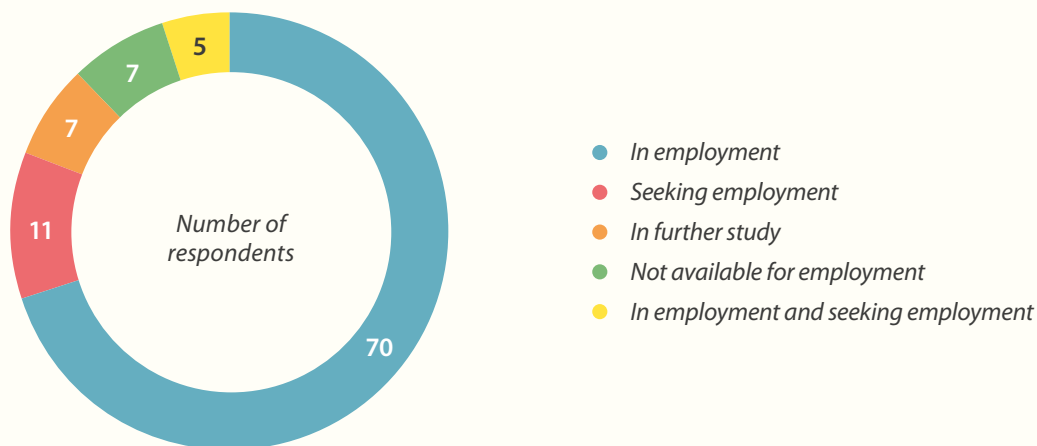


Figure 2.4: Respondents categorised by employment status

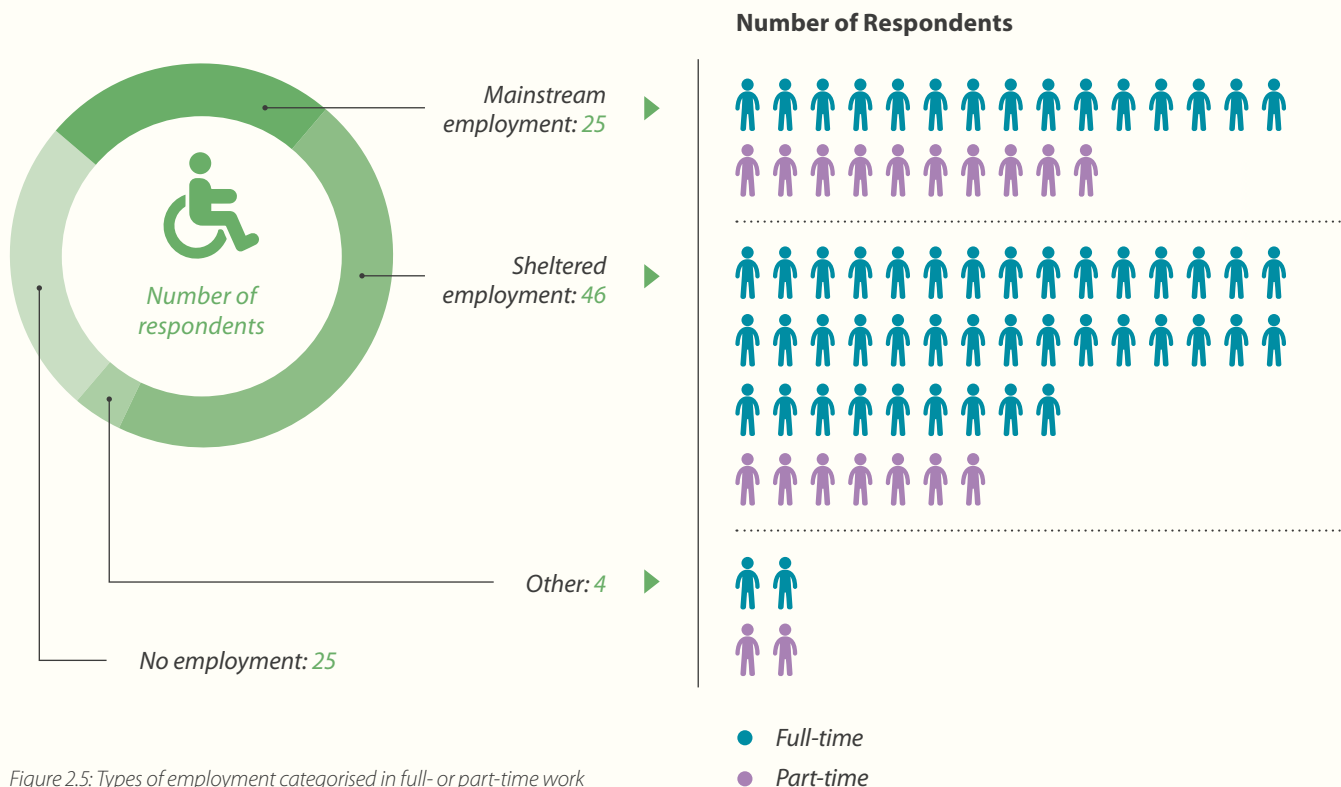


Figure 2.5: Types of employment categorised in full- or part-time work

The majority of employed respondents, both in mainstream and sheltered employment, were in clerical and production jobs

which involved packing, photocopying, binding, typing and other paperwork.

	Mainstream employment	Sheltered employment	Other
Professional and managerial	2	1	1
Technical	1	2	0
Clerical	14	11	0
Sales and services	7	4	0
Production and related	0	18	0
Cleaners and labourers	0	7	0
Others	1	3	3
TOTAL	25	46	4

Table 2.5: Type of employment by employment category

LOW SALARY

The Figure 2.6 below shows that those who are in mainstream employment earn a higher average monthly income than those who are in sheltered employment. The majority (62) of our respondents earn less than \$1,500 per month. Those working in

sheltered workshop full-time receive a median monthly allowance in the range of \$200 and \$499, while similar part-time workers receive less than \$199 per month. Such low wages made the majority of respondents anxious about their financial sustainability and employment opportunities. The low salary levels of the sheltered programmes are insufficient to meet the costs of the needs of PWDs.



Figure 2.6: Salary levels across different types of employment

Forty-two of our respondents clearly stated that their salary was low and insufficient. Some work for as low as \$6 an hour, or get paid for tele-surveying based on the number of surveys completed. While they feel that they deserve to be paid more for the jobs entrusted to them, Respondent82 feels resigned to this reality because “as long as they accept you, you have to accept what is given.” Some liken what they earn at a sheltered workshop to an allowance, rather than a salary, highlighting the meagre pay. These respondents were able to get by because the majority of their living expenses were taken care of by family members. While this arrangement may have been acceptable for the present, many in this group feel anxious about living independently in the long term, given their degree of reliance on family members (discussed further in Section H). This anxiety is compounded by a lack of savings, uncertainty about their health and employment opportunities, and their inability to rely on their ageing family members. As Respondent88 noted, “I have no savings. I feel like I can die, but I cannot get sick.” This statement underscores the stress that people in this situation experience, when they are barely getting by but are aware that ageing will bring greater expenses. Many are already struggling and are merely one illness or crisis away from falling into extreme poverty.

“I have no savings. I feel like I can die, but I cannot get sick.”

Wage stagnation is also an issue. Four respondents have been working for more than a decade in the sheltered programmes, but their salaries have either not increased, or have increased only marginally. Such minor wage adjustments have not kept up with the rate of inflation in Singapore, or the rise in transportation expenses. Respondent69 adds, “Taking a taxi on a rare occasion makes my monthly budget go over.” Respondent84 also explains that he can barely get by; if he goes to a movie once, he must eat instant noodles for a week to make up for it. Such poor wages further increase their social isolation.

Respondent20 reported that the same job can command a higher salary in mainstream employment, but that there are too many challenges in securing a job in the open market. Similarly, Respondent4 took a lower-paying job in a sheltered programme because the toilets and transport were not accessible in the previous place of work, despite a higher salary. Respondent8 talks about his experience applying for jobs and working in mainstream employment: “I can work normally, but my pay is low. Before this job, I was job hopping because nobody wanted me.”

DISCRIMINATION

Many respondents offered accounts of discrimination, either in their attempts to secure a job, or while they were working. Respondent96, despite being qualified for the mainstream job she had applied for, did not get hired because those overseeing the hiring process felt she may not be able to cope in case of an emergency in the building. Another respondent reported

feeling dejected that he was unable to get a job in the area of his academic qualification; “people just don’t want me,” he remarked. This feeling was echoed by other respondents, one of whom said,

“I am capable, but employers reject me just because I am in a wheelchair.” Some respondents have learned that it is safer not to declare their disability in order to get an internship or job interview.



Respondent #90

He is a 27-year-old man with a congenital disorder since birth and many physical challenges. He needs help with almost all his ADL and IADL activities. He has never walked and is unable to carry anything heavy, including a textbook. His condition seems to be deteriorating. He has a full-time domestic worker whom he relies on heavily. He spends most of his days sitting on an office chair and at the computer at home. He has completed a degree and is looking to be gainfully employed. He has been looking for a job for seven months and has attended more than five interviews. He does not declare his disability when he applies for jobs as he believes that will substantially reduce his chance of even being called for an interview. During his internship, he had difficulties, and had to be exempted because MOM rules did not allow him to be accompanied by his domestic worker to work.

In other cases, respondents report having left job situations in which it was clear that they were either being treated poorly because of their disability, or because employers were not willing to be flexible with time. For example, Respondent49 left several administrative jobs because of the long hours; in some cases he was asked to leave, and in others he quit because he was not allowed the flexibility of time. Another respondent also felt compelled to leave a job because of the negative manner in which his boss treated him. Respondent12 found that he was paid much lower than his peers for the same job in an IT company, and he decided to leave and work on his own. In some cases, the contracts of the employees were simply not renewed without any indication of reasons, leaving the respondents wondering if discrimination had occurred.

SHELTERED EMPLOYMENT

The respondents who participate in sheltered employment offered mixed opinions about it. On the positive side, people tended to

cite the opportunity to get out of their homes, the chance to work, good work environment, having job responsibilities, and being among people with similar needs, as beneficial to them. Those who were engaged in sheltered employment generally reported that their job responsibilities had been adjusted to match their disability: receiving extra time to meet deadlines at work, flexible work hours and their workplace being ergonomically modified to suit their needs. However, several people participating in sheltered employment felt that they did not see much of a future in their current role, and had few career prospects. They also complained about their low pay and saw working with colleagues who had other types of disabilities as a disadvantage. Respondent10 said that sheltered employment “feels like prison or school, and a waste of time.” While many had understanding employers and colleagues that they could count on for support, they still faced difficulties when dealing with customers who treated them unsympathetically. While a majority of those in sheltered programmes felt they had a good network of colleagues and friends at work, some found it challenging as they did not get along with colleagues at work.



Respondent #76

She is a 42-year-old woman who developed bone cancer at the age of 13. She has been married for 14 years and is close to her siblings who provide her with emotional support. The bone cancer resulted in the amputation of her leg and she had to undergo chemotherapy for three years, which resulted in a lot of side effects such as vomiting and hair loss. She has been using crutches for 26 years and this hurts her back, which resulted in a secondary condition of scoliosis. She reported that her parents could not accept her disability and tried to hide her from the world. She has been under a sheltered employment programme for 26 years, working full-time 40 hours a week. She worries about her future prospects. She would prefer open employment, especially in an area of interest to her, but she is worried about transportation from home to office. She has previously resigned from her sheltered workshop position due to unreasonable deadlines, but after a week of staying at home, she got bored and went back to work. Ideally, she would like to run her own shop but “rental is too expensive” and she reports feeling afraid.

The picture that emerges here is that sheltered employment meets some needs of some people with disabilities, but not others. Ironically, the location of many sheltered workshops poses significant travel challenges for many people with disabilities, leaving them with little choice but to pursue mainstream employment (discussed further in Section G on transportation). Further, sheltered employment is often very repetitive and monotonous, leaving some feeling their skills are not being optimally used.

SIGNIFICANT FACTORS IN JOB SATISFACTION

The majority of our respondents reported that the reason for positive experiences at their workplaces, whether in sheltered or open employment, was the presence of a support network of people at work. Twenty-five of the respondents who worked in sheltered programmes reported that this was the most important aspect of employment for them. Often, this role was filled by a supportive colleague or an understanding supervisor; occasionally, it was a social worker who they could approach for assistance in other aspects of their life. Eight respondents experienced the same sort of support in their mainstream jobs too. Some who were in sheltered programmes had transportation provided for them, which eased their situation significantly. Six respondents who were artists reported that they got to exercise their creativity by doing work that they loved. One respondent reported learning a lot at work.

More of the respondents in open employment are in jobs that they find satisfying. Further, our respondents offered several examples of open employment situations that worked well for them, and where their needs were acknowledged and met. Employers in the open market who carved out roles based on the respondents' skills and strengths also contributed to the respondents' positive experiences of employment. Four respondents described this type of scenario. Three employers also made workplace modifications, such as altering the heights of the cupboards, or installing sliding doors. One employer, after the first experience of hiring our respondent, sought to hire another disabled individual in order for them to have a support system at work.

Eight respondents benefited from having flexible working arrangements, whether it was working from home or working part-time, or not having strict hours imposed on their schedule. An employer in the mainstream market went to the respondent's home to conduct an interview for a home-based job. There were two other such employers who gave their employees one year unpaid leave when they became disabled through accidents and, upon their return, changed their work responsibilities to suit their new physical condition. Another employer, after an employee's accident, paid six months' salary during medical leave as well as six months of unpaid leave after that to ensure an easier transition back to work.



Respondent #56

She is a 32-year-old woman who recently had an accident while on vacation, paralysing her from the waist down. Her employer immediately placed her under the prolonged illness support whereby she was given full salary for the first six months and received half a month's pay for the following six months. At the end of her leave period, she was offered a desk-bound job. While the pay was lower than what she had previously earned, she believes that it is commensurate with the job responsibility. During our interview, she had just returned to work. While her employer has been supportive and understanding of her predicament, the respondent worries about her depleted insurance and the pressure to maintain her paid job, which is the only source of income for her and her mother.

While the above examples are by no means indicative of the experiences of all people with disabilities in open employment, they indicate that a supportive employer may make a big difference to people's experience. This often involves an environment conducive to support, assigning tasks that match the strengths of the employees and offering some flexibility around hours and location. The above examples show how the advantages of mainstream employment (such as good career progression, better salary, etc.) can also include the advantages of sheltered employment (employers who have an appreciation of the unique needs of PWDs, and who are willing to make flexible arrangements for them).

CHALLENGES FACED AT WORK

Fifty-four of the 75 employed respondents faced some challenges at work. These were mainly related to their physical condition and the impact that it had on their work. Respondents reported issues such as their eyes swelling from working at the computer for too long, their hands growing numb or aching, and various difficulties from sitting continuously for long hours. In some cases, their jobs involved a great deal of travelling, walking long distances or long working hours. This caused both physical and mental stress, hence undermining self-confidence.

Due to challenges our respondents faced in getting any form of employment, people often accepted jobs where there was a mismatch between their skills and needs, and the job's requirements, just to earn some income. For example, Respondent33 took a cleaning job in spite of her allergy to detergent. Others would take physically demanding jobs beyond their capabilities, or simply accept jobs without having the skills for them. This contributed to a vicious cycle of not being able to perform the tasks, becoming unemployed and having to seek new jobs.

Some have also faced communication challenges because of how their disability affects their speech, or because they work with people with mental disabilities who had difficulties with communication. For example, Respondent84 works as a supervisor in a sheltered workshop, and his peers are unable to follow his instructions. He compensates for this by scrutinising their work more closely, which means additional work for him. Several respondents reported feeling that their employers could

not understand their needs, and had high expectations without making adjustments that would allow their employees to meet these expectations. These circumstances and the fear that their disadvantages would undermine their competitiveness caused some people to resign from their jobs. Some respondents wanted more meaningful jobs that they were capable of doing “not just production or call centre jobs.”

Respondents offered several instances where mainstream jobs did not take their unique needs into account. For example, some said that because of their disability, their company benefits did not include insurance. Further, there are no specific provisions for people with disabilities in the Work Injury Compensation Act.³² Some respondents tried to get around these issues by choosing to work from home, but that choice was not without its consequences. While some felt bored working at home, Respondent59, after having worked from home for many years, lamented her lack of social life as a result of that.



Respondent #59

She is a 27-year-old woman who quit her home-based job recently because her health condition was deteriorating. She lives on her own since her mother's death three years ago. She lost contact with her father when she was young. She can still walk, but gets tired easily. She uses crutches and special shoes; however she has been bound to a wheelchair in recent times. She has worked for eight years in a home-based job, marketing products. She says that her legs and fingers get numb and her shoulder gets stiff when she spends too much of time on the computer. She has been declared medically unfit for work for the past six months. She has stopped working to attend rehabilitation sessions. She has sought help from the local Social Service Office (SSO) and has been receiving \$300 a month. She uses the money to pay for her rent, groceries, food, phone bills and internet. She mostly depends on donations to cover her living expenses.

In addition to facing challenges in their present job situations, many respondents also worry about the future. For example, they worry about supporting themselves when between jobs, not having the raise in salary to correspond to the rising cost of living in Singapore and lacking future job prospects. Respondent44 worries about performance appraisals that might highlight areas of weaknesses rather than focusing on his strengths. Some also worry about securing work in the future, and managing the stresses that come with being employed in an environment where their different needs are not properly understood. Respondent40 feels that “employers are quick to judge since I am in a wheelchair and this causes problems with getting a job. Maybe employers feel that I am unable to do what others can do, but in fact I am capable.”

Respondent5 has a low education level and reports lacking the confidence it takes to approach employment opportunities, further worsened by how others perceive his disability.



Employers are quick to judge since I am in a wheelchair and this causes problems with getting a job. Maybe employers feel that I am unable to do what others can do, but in fact I am capable.”

32 Work Injury Compensation Act, Revised Statutes of Singapore 2009, <http://statutes.agc.gov.sg/aol/search/display/view.w3p;page=0;query=DocId%3A%22f585b449-8f09-4c7d-bc08-c0d33766820b%22%20Status%3Ainforce%20Depth%3A0;rec=0>.

Section E: Finances

Given the combination of challenges that our respondents face, it is perhaps not surprising that many have financial difficulties. This section looks at their sources of income, types of expenditure, and concerns about the future.

FINANCIAL INDEPENDENCE/INTERDEPENDENCE

The majority of the respondents in this study can be classified as financially dependent. Although some can manage their own expenses, almost all depend on family members and VWOs for other forms of support such as housing, food, transportation, etc. For example, Respondent96 contributes to his household expenses, while his parents provide him with housing. Similarly, Respondent40 manages many of her financial needs, and does not take any pocket money from her

parents, but she depends on them to pay her annual medical check-up costs.

SOURCES OF INCOME

As shown in Figure 2.7, after paid work, parents and siblings are the main sources of financial support to our respondents. Of the seven respondents who are currently married, three receive financial assistance from their spouses, and none have listed children as their source of financial support. This is not surprising, as only two respondents in this study had children who are 18 years or older, and of these two children, one was studying and the other was in National Service. Ten respondents reported receiving financial support from a VWO.

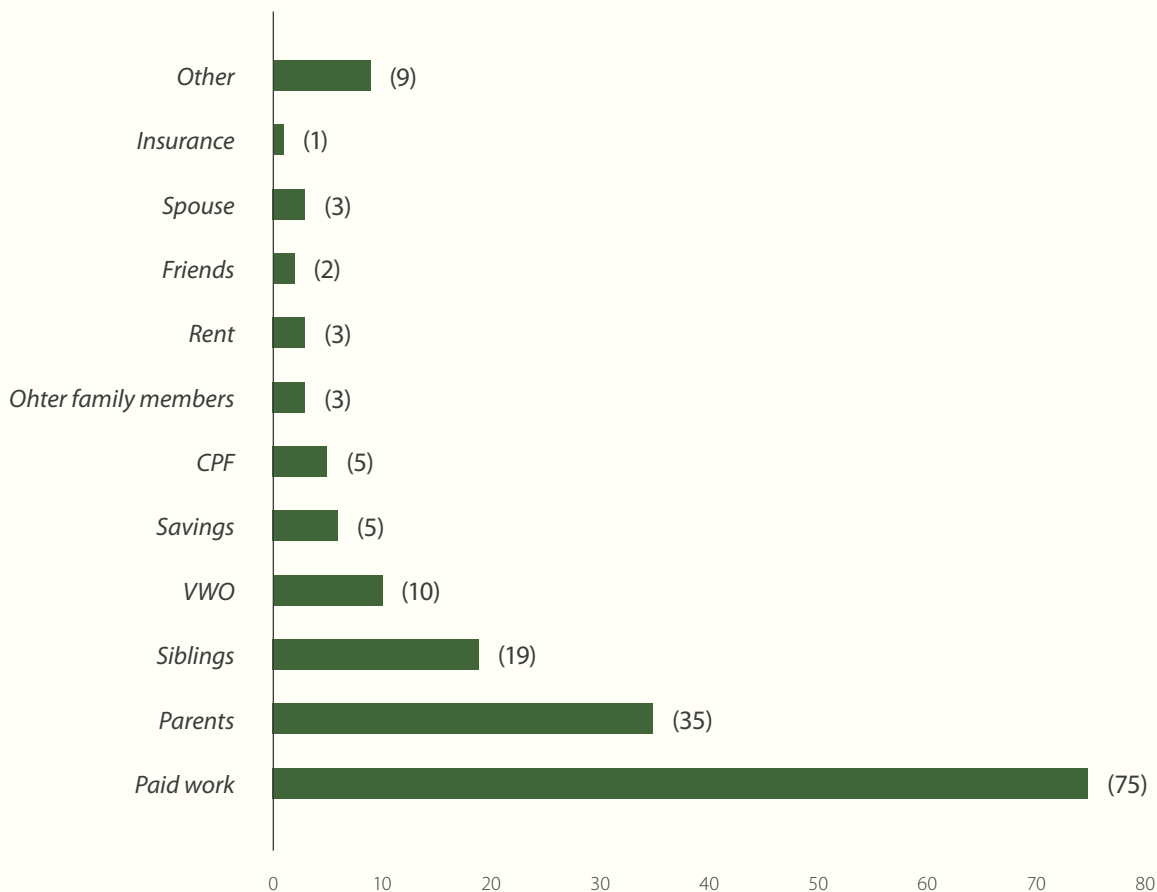


Figure 2.7: Sources of income

Figure 2.8 shows the various sources of income for the 75 employed respondents. Income from paid work alone supports only 27 respondents; others depend on various

sources of financial support, most often their parents. In some cases where respondents are partially supported by family members, those who are supporting them have low income.



Respondent #39

He is a 37-year-old man, who lives with his widowed mother. He has been ill for over 10 years, and his mother is the main caregiver. He attended school till Primary 5, but dropped out because his alcoholic father used to abuse his mother and he lost interest in education. He started working as a newspaper delivery boy. He works part-time and earns \$68 a month. Because of his low income, he relies on his mother for additional support; she earns \$300 monthly. His brother also lives with them, but does not contribute financially to the household, meaning that this family of three lives on \$368 a month.



Figure 2.8: Sources of financial support for those who are currently in employment

Among those who are currently unemployed, 16 out of 25 respondents also listed parents as the most important source of financial support.

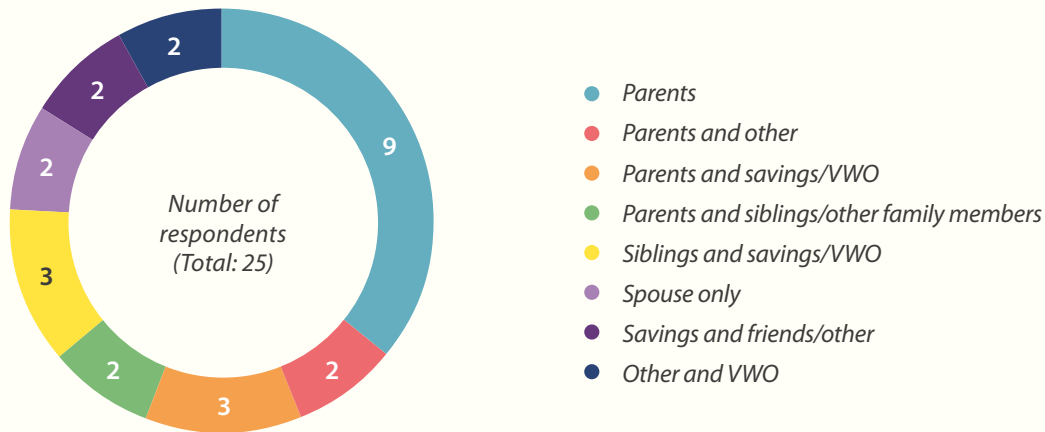


Figure 2.9: Sources of financial support among those who are currently unemployed

TYPES OF EXPENDITURE

Several respondents reported spending a high percentage of their income on medical supplies. For example, Respondent 56 spends a quarter of her monthly salary – her only source of income – on medical and care supplies. Respondent 63 spends more than half of her monthly income on alternative medicine, which she feels she needs for her recovery. In some cases, “medical and care supplies” include items that would not typically be put in this category, but which are necessary for the comfort of the respondent. For example, Respondent 95 explains that, “In addition to diapers and catheters, which cost a lot of money, I have to fork out between \$500 and \$600 to replace my cushions.

Without cushions, as I have to lie on the bed mostly, I will get bed sores.” There are others who purchase medical care items from neighbouring countries to reduce their medical costs.

Those who must take taxis for transport reported it as a major expenditure. For example, Respondent 64 does not qualify for taxi subsidies through means testing and spends half of his income on taxi fares. Even when respondents do qualify for taxi subsidies, they still must pay the fares at the time of travel, meaning that it is necessary to have the cash on hand. Further, taxi subsidies range from 20 to 50 per cent of total monthly fares, depending upon per capita monthly household income, so even with subsidies these expenses can still be significant.³³



Respondent #32

She is a 27-year-old woman who developed leukemia 15 years ago and has difficulty walking. She lives with her mother (who suffered a stroke recently and also looks after her own mother), sister, stepfather and grandmother. Her elder brother is married and lives elsewhere. Her sister is currently a student and the respondent’s primary caregiver and source of emotional support. The respondent is the sole breadwinner of the family, working full-time as a clerical officer, dealing mostly with calling clients and data-entry. She earns between \$500 and \$1,000 per month, and spends almost 70 per cent of her salary on taxi fares, some of which is eventually reimbursed through the taxi subsidy. If her payment gets delayed, the family of five has less than \$300 a month. She uses her monthly earnings to pay for medical bills and food, and she gives money to her mother and sister. After acquiring leukemia, she had difficulty walking and had hip replacement surgery. Since then, she has been using a wheelchair. The respondent feels additional pressure as a result of her mother’s recent illness and demand for more financial support from her. According to her, her mother says, “You are the only one I can depend on.” Challenged with her own deteriorating medical condition and a plan to start her own family, she feels pressured to make tough choices.

33 “Taxi Subsidy Scheme,” SG Enable, <https://www.sgenable.sg/faq/schemes/taxi-subsidy-scheme-tss-for-persons-with-disabilities/>.

For those who had to rely on full-time domestic workers for caregiving, they had an additional cost component. Respondent58 paid a monthly salary of \$600 to his caregiver, who is a foreign domestic worker. While he is eligible for subsidies, he reports they do not help much. Respondent56 pays the same amount to her mother, who plays the role of caregiver.

SAVINGS

Given the challenges of limited income combined with several types of expenditure, unsurprisingly, only 16 of

our respondents mentioned trying to put aside savings. Respondent28 manages to save half of her salary because her parents give her about \$10 a week for spending and she does not need to spend on transportation. She is an outlier, though, in being able to save so much. Respondent8 tries to save, but ends up spending everything by the end of the month. Respondent87 reports having saved “a little,” but feels like she does not have enough savings to sustain her for long. Nine respondents mentioned specifically that they were not able to save, and three respondents were currently spending the savings they had previously set aside.



Respondent #22

She is a 37-year-old woman who suffered a brain aneurysm about three years ago. She lost control of her left limb after undergoing surgery. She needs help with activities that require two hands, for example lighting a stove or hanging clothes. Other than that, she manages most of the activities on her own. However, because she lives with her elderly parents, she gets some help from their domestic worker. She is financially independent when it comes to taking care of her own needs. She saves as much she can from her income through her paid job. She works from home assisting her director who lives abroad in managing his local business activities. She saves money on transport as a result; she also gives her mother some money every month. For now, she does not worry about her housing costs, as she lives with her brother who is single and owns the house.

Only 12 respondents have some type of financial plan for the future. They try to budget their expenses and plan to stay employed for as long as possible. Some hope for more help from their families as part of their plans for the future. For example, Respondent85 believes that his father will eventually give him some money. However, he is not confident that it will be enough, especially when there is inadequate money for food now. He reports having little hope about the future, and does not like to think about how he will manage after the death of his parents.

MANAGING FINANCES

Several respondents reported that they had help from others to manage their finances. Respondent71, for example, earns between \$200 and \$500 a month, and gives her monthly salary to her parents. They in turn give her \$10 every day for her expenses. Respondent37 has the same relationship with her father: She gets \$10 from him, and he holds her ATM card and manages her salary. She says that her father keeps a check on her account,

and scolds her when she overspends. Respondent 10's mother keeps her ATM card and manages her expenses, but reminds the respondent when she gives her money that the money is her own. Respondent73 gets \$50 monthly from his brother who holds his ATM card and pays for all other expenses.³⁴

MANAGING WORRIES ABOUT FINANCES

Given these challenges, 30 of our respondents reported worrying about their finances. Many respondents cited the lack of employment opportunities, or their low salaries, as the cause of their financial worries. Six respondents reported being concerned about finances largely because they needed to earn a salary that would allow them to pay for their medical expenses. Many explained that they were concerned about the interplay of their health concerns and their employment prospects. One respondent asked, “How long will I have eyesight? Financial cost for medication is very high and I am seeking employment.” Another explained, “Not enough

34 It is beyond the scope of this research to analyse these financial relationships. Our research instrument was only concerned with the perspective of the person with disabilities; without interviewing their families and gaining a better understanding of family finances and relationships, it is not possible to gauge the nature or intentions behind these arrangements

money if I am unable to work, but my health might get worse, thus burdening my family.”

Five respondents, who currently depend financially on family members, worry about what the future may bring. Respondent5, for example, worries about his financial situation after his sister starts her own family. Respondent7 and Respondent33 both expressed anxiety about their fates after their parents pass away; one is considering seeking financial assistance from VWOs as a way to address the problem, while the other is hoping to find a better-paying job. For Respondent62, her housing loan is a cause for concern, as she can no longer afford to pay it now that she requires surgery. At the time of her interview, she had stopped payment on her housing loan in order to pay her hospitalisation bills, but this is clearly not a sustainable solution.

The cost of caregiving or hiring a caregiver causes similar financial worries. Hiring a foreign domestic worker is one of the more expensive options for home-based services and, as discussed in section B, is an unaffordable option for many respondents. SG Enable maintains a database of various VWOs that provide some home-based services on a part-time basis, but not all types of disability services are available. For example, according to SG Enable’s “Service Matrix,” it does not appear that home-based speech therapy services are available.³⁵ In addition to home-based services, there are now subsidised part-time services that are available. Whereas once there were only subsidies available for people with disabilities who attended day-care facilities on a full-time basis, there are now subsidies available for those who attend on a part-time basis as well.³⁶ While there is some choice in professional care services for people with disabilities, there is still some distance to go towards more customised and more comprehensive options.

In addition to caregiving services, there are also various types of financial assistance available. PWDs can get some assistance with transportation. However, even with subsidies, taxis are still too expensive for many to use on a regular basis (see Section G for further discussion about Transportation). For Respondent86, her daily expenditure on taxi fares led her to resign from her job. Other types of transportation are prohibitively expensive too; Respondent72 takes company transport to work every day, but the transport cost is still too high for him to afford on his low salary. Financial assistance can also serve to help those who are in need of purchasing assistive technologies, such as a light-weight wheelchair, to facilitate their daily living activities, thus encouraging independent living.

Due to the policy of family means-testing, though, many respondents are not eligible for certain types of financial assistance. Respondent64, in his late twenties, is employed, but spends almost half of his salary paying taxi fares, and uses the rest to cover all his other expenses. He is not eligible for subsidies as he did not pass the means test. He says, “If I am working, I am independent; my parents have a sibling to care for.” He believes that it is unfair for the means test to look at the average income earned by his family, and not him alone. Family means-testing takes into account one of two factors: either gross household income alongside the number of people living in the household, or, for households with no income, the annual value of the residence.³⁷ This type of means-testing assumes that family members within the same household will care for one another, and promotes the “family as the first line of support” social policy of Singapore. That this is a value promoted by the Singapore government does not, however, guarantee that it works out in actual family units. As Respondent64 points out, there can be many diverse and expensive needs in a household, and means tests for individual services may not take all of these into account.

Section F: Housing and domestic arrangements

HOME OWNERSHIP AND INDEPENDENCE

Eighteen respondents either owned or co-owned (with a spouse, parents, or siblings) the units in which they lived. According to Housing and Development Board (HDB), over 70 per cent of Singaporeans own HDB flats (i.e. 90 per cent of the 80 per cent living in HDB flats own their flats).³⁸ The percentage of HDB owners among our respondents is clearly far lower than

the national norm. We found no relationships between type of disability or the number of siblings and home ownership. Among the seven respondents who owned the units in which they lived, three respondents bought the units on their own, and the rest inherited the houses from their parents. The majority of respondents (52) are staying in houses owned by their parents. Of those staying with their parents, 35 respondents live with their siblings as well.

35 “Service Matrix for Home-Based Care Services,” SG Enable, <https://www.sgenable.sg/wp-content/uploads/2015/02/HBCS-Service-Matrix-5-Jan-2015.pdf>.

36 “Subsidies for Disabled in Part-Time Day-Care,” Ministry of Social and Family Development, <http://app.msf.gov.sg/Press-Room/Subsidies-for-disabled-in-part-time-day-care>.

37 “Subsidies for Government-funded Intermediate Long-Term Care Services,” https://www.moh.gov.sg/content/moh_web/home/costs_and_financing/schemes_subsidies/subsidies_for_government_funded_ILTC_services.html.

38 “Public Housing in Singapore,” Housing and Development Board <http://www.hdb.gov.sg/fi10/fi10320p.nsf/w/AboutUsPublicHousing?OpenDocument>.

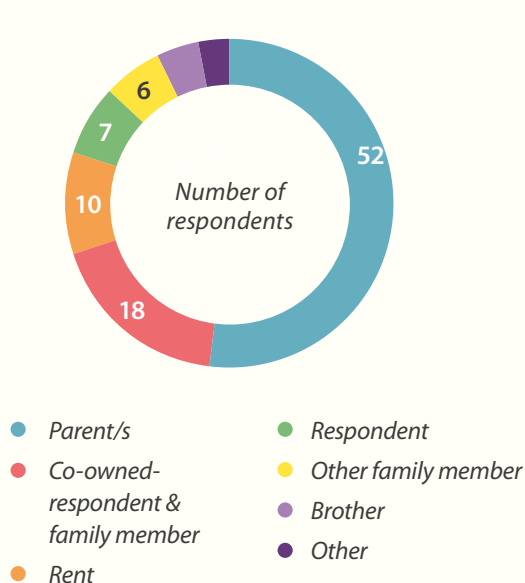


Figure 2.10: House Ownership

There are many obstacles that can preclude people with disabilities from living independently. Physical barriers, rising housing costs and low incomes preclude home ownership for many. Five respondents reported facing difficulties due to the design of their homes. Respondent75 ultimately chose to move into a nursing home in 1978 when he realised the difficulty of finding a home with a design that would meet his needs. In contrast to these situations, Respondent58, who co-owns a home with his mother, managed to customise his house to suit his needs. These renovations include lower stoves, wheelchair-friendly toilets, handles next to the bed, and so on. Such alterations are expensive, and Respondent58 was in a unique position to afford them because of the stable income from his full-time job, his multiple side jobs, and the cash prizes he has won from competitions.

As discussed in Section D on employment, many respondents do not have the income to support design changes to their homes. Even without renovations, many respondents are not able to afford their own homes. The typical salary of a disabled person is not high enough to keep up with the rising costs of housing in Singapore. Further, housing loans reduce savings, which for many must be kept intact to pay for health care costs.

RELATIONSHIP WITH OTHER HOUSEHOLD MEMBERS

Not having physical and financial independence can alter the quality of the relationships within a household. Being able to feel like an equal and not a burden because of a disability, is a challenge to many respondents.

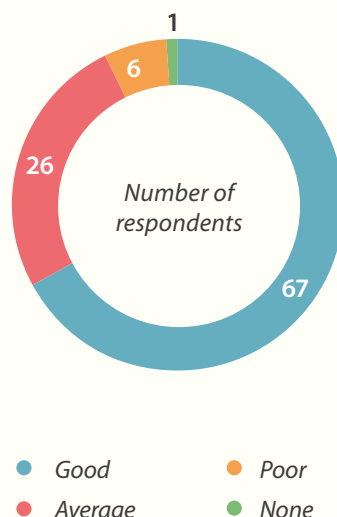


Figure 2.11: Relationship with household members

Three respondents are living alone due to the lack of family support. Respondent59 used to stay with her mother in their rental flat until the latter’s death, and now she has no family members to live with. Similarly, Respondent20 has also lived alone since her parents passed away; her sister visits, but her sister’s husband is in a wheelchair and needs caregiving assistance too. Respondent94 lived with a friend until she bought a flat under the Single Singapore Citizen Scheme when she became eligible for it four years ago.³⁹ Her mother visits to assist her with cleaning and cooking, but she has bad relationships with her father and brother.

As shown in Figure 2.11, six respondents reported poor relationships with member(s) of their household. Respondent85 lives with his parents, brother and sister-in-law, but prefers to keep to himself and not ask for their help. While he tries to be optimistic, he says that he will try to move into a nursing home if his disability worsens and he is in need of care. Respondent27 explained that he used to rent a room at his friend’s flat, but that their relationship soured, and he has since had to seek his Member of Parliament’s (MP) help to get a rental flat. He is currently co-renting from HDB with another friend.

Many of the housing arrangements described in this section are unstable as they are intertwined with caregiving; that is, the death of a family member, or simply a change in circumstances of those living in the same household, might precipitate the sudden change of a housing arrangement. In some cases, the lack of certainty surrounding houses has had serious consequences for our respondents.

39 See “Eligibility To Buy: Single Singaporean Citizen Scheme,” Housing and Development Board, <http://www.hdb.gov.sg/fi10/fi10321p.nsf/w/BuyResaleFlatSingleScheme>. Under this scheme, single Singaporeans may buy an HDB flat from the open market if they are 35 years old or above, or widowed or an orphan. In cases where they have not had an HDB subsidy before, they may apply for the CPF Housing Grant for Singles, see “CPF Housing Grant for Singles,” Housing and Development Board, <http://www.hdb.gov.sg/fi10/fi10321p.nsf/w/BuyResaleFlatCPFGrantSingles?OpenDocument>.



Respondent #27

He is a 42-year-old man who had a spinal cord injury and became paralysed after an accident at his workplace. He recently underwent further surgery for injuries associated with prolonged sitting in a wheelchair. His parents passed away and he has lost contact with his siblings after his accident. He was married to a non-Singaporean woman who took his money and left him after three years. He recently moved into a new rented flat where he lives alone. Previously, he rented a room from a friend for three years and when he had problems with his friend, he went to meet the MP of his district and appealed to rent another flat, which is the current one he is living in. In the past, he was homeless and stayed at void decks for two years before getting the MP's assistance in renting a flat.



Respondent #47

She is a 27-year-old woman with spina bifida at birth and is unable to feel from her waist down. She is the eldest in the family and has two brothers. Currently, she stays with her family, and the house is jointly owned by her and her mother. Her parents have been divorced since 2007 as her father used to gamble excessively. They had to buy and sell houses multiple times due to this. She and her brothers have also been sent to children's homes when they did not have a house to stay in. As the homes were not wheelchair-friendly, she was transferred to multiple homes.

Section G: Transportation

IMPACT ON EDUCATION AND EMPLOYMENT

One of the important factors that influenced the respondents' experiences at work and school was the availability of accessible transportation. Several have rejected work opportunities because of the lack of transport facilities. As mentioned above in Section D on employment, sheltered employment often poses transportation challenges, as they are only located in specific areas of Singapore. Employment decisions are immediately circumscribed by transportation considerations. Similar problems exist in the sphere of education: Respondent80 had to travel for 1.5 hours each way to attend the nearest junior college that was wheelchair-accessible. Another respondent turned down internship offers due to travel issues, and Respondent92 stopped schooling because of the lack of accessible transport facilities.

CHALLENGES WITH CURRENT TRANSPORT SERVICES

Nineteen respondents described facing several specific challenges with transportation. First, not all buses are disabled-friendly, and buses or trains are often too crowded. Commuting in the peak hours was almost impossible for many respondents, which made open employment challenging for many. Further, long travel time was a strain for them, and some reported

that the train door closed too quickly and caused accidents. Similarly, the gaps in the train platforms were a challenge for some respondents. While taxis are often the most disabled-friendly form of transportation, financial concerns limit how frequently most people can take them. A 50 per cent taxi subsidy is considered by many to be insufficient; some have had to change their job, because the only reasonable way to get to work is by taxi, and they can no longer afford it.

Respondents using aids faced even greater challenges when using public transportation. Several pointed out that bus stops had no waiting area for people in wheelchairs. Moreover, those with motorised wheelchairs could not use taxis, and travelling on buses was a challenge too. For those able to walk using crutches, walking in public was difficult, as people moved quite fast and frequently stepped on their toes.

While many felt that buses were generally better than other modes of transportation, several had experiences with rude or unhelpful bus drivers. In addition, several respondents felt that the general public were not willing to give them space or seats, even when they were using crutches. Other respondents explained that they occasionally had problems boarding buses, because others in the queue would not give way to them; this significantly increased their travel time.

Section H: Worries for the future and support services

While this section provides a discussion of service changes that our respondents would like to see, many of our participants expressed concerns that cannot be addressed by specific policy or service changes. However, these worries are no less important in helping us understand the perspectives of people with disabilities and the challenges they face.

Seven respondents reported having concerns about marriage and building a family. They asked questions such as “Will I ever settle down?” and “What if I grow old and there is no one with me?” A few asked “Will there be someone who can accept me as I am?” The insecurities that people with disabilities feel about how they are perceived are exacerbated by society’s attitudes and perceptions of them. For Respondent32, her concerns about her future family also include her ability to reproduce, which is uncertain. Respondent67, in addition to worrying about finding someone to start a family with, is also concerned about the financial responsibilities that might be difficult to meet with his low salary.

When asked about their future worries, nine respondents were not able to give direct answers, but instead talked about a feeling of powerlessness. Respondent26 stated “I cannot say anything, cannot do anything, so why ask this question?” Respondent50 simply said, “I seriously don’t know what I can do about my future.” Respondent 29 and 31 both appeared to be flustered by the question, and said they “don’t know where to start” or “can’t express it in words.” On the other hand, both Respondent35 and Respondent70 chose to ignore their worries as a coping mechanism, saying that, “if I start to think, it’s not a good thing” and “there are too many issues, I don’t want to talk about it and don’t want to complain.” This overwhelming

sense of worry has had very real effects on some respondents. For example, Respondent10 claims to worry “constantly” and has been hospitalised twice due to his stress levels.

Four respondents cope with their worries by turning to their religion. Respondent37 says, “I leave it to God.” Similarly, Respondent29 says, “I don’t think about the future and let God take care of it,” and Respondent43 says, “I do my best and leave the rest to Man in the sky.” Finally, Respondent75 explains, “I take things a day at a time, leaving everything else to God.” It is important to note that, at least in two of these cases, the respondents specifically state that they are also trying their best to cope with their worries, and rely on God for help. This should not be confused with “giving up.”

SERVICE AND POLICY RECOMMENDATIONS

As part of our interview process, we asked open-ended questions about the types of services that our respondents would like to see implemented, as well as which current services they believe should be improved. Because we found many of our respondents through service-providers, it is not surprising that the majority were already receiving services from one or more VWOs: 66 respondents were either receiving, or have received some type of support from VWOs in the past. The majority of respondents (55) have had assistance with employment, 21 have had help with physical therapy and 16 have received education aid. Ten are currently being helped with transport, and eight receive financial assistance.

A total of 47 respondents spoke of a need for further change. The following are some of their suggestions.



Respondent #63

She is a 22-year-old woman who is working in a sheltered workshop. She graduated from a local university and has other aspirations for her career. About the support services, she says, “I am not entitled to many. There is an issue. For example, I want to learn driving. To get approval from Traffic Police, I need to get a medical report. Every organisation has its own doctor. Each service I apply I pay \$89.90 to get a doctor’s certificate. I cannot apply for a foreign domestic worker grant because I don’t pass the means test. I suggest that maybe there can be one certificate for all services and maybe we just get checked once year. If I have a permanent illness, why must I get tested every time? And there are so many hidden expenses that you do not know until you explore with Land and Transport Authority (LTA) and MOM for foreign domestic worker grant, therapy.

Respondent #59 had to wait for one month after her application for a wheelchair. She says, "I was in a terrible condition financially and otherwise. I bought a wheelchair at the retail price of \$275." For her motorised wheelchair and mediwheels, she went through the social workers in the hospital which was faster. She adds, "I passed the means test based on income."

GENERAL CHANGES

Many of our respondents' proposals touched upon the structure of service provision in Singapore. For example, some respondents suggested that accessing services would be less challenging if there were less paperwork involved. The need to cut down on bureaucracy was mentioned repeatedly in interviews with two other vulnerable communities in Singapore – low-income elderly and single-parent families⁴⁰ – and appears to be a fairly typical suggestion. Along similar lines, several respondents suggested that services should be streamlined, particularly for those who require multiple services. That is, rather than having people seek help from multiple sources, there could be a system by which receiving one type of help automatically puts them into a system that checks their eligibility for other types of assistance. The government has already taken some steps in this direction with the Social Service Net (SSNet) which will be a new case-management system that will allow for more data to be shared amongst service providers, to increase efficiency.⁴¹ Further, the government plans to set up 20 SSOs throughout Singapore over the next two years, which are designed to be one-stop offices in which people can learn about the various types of help that are available to them.⁴² In addition to these steps, some proposed that there should be an enhanced triage system, so that people with immediate needs might receive service more quickly than is currently the case. Finally, many respondents suggested that available services should be better publicised, so that there might be less effort required to learn what is available, and less chance of missing out on services for which one is eligible.

Some respondents also suggested that services should be provided on the basis of individual needs rather than family needs. Because the current system requires that the family finances be reviewed to determine service eligibility, some participants failed to pass the means test, even though, as individuals, they

were struggling significantly. They argued that the family test was inherently unfair: Although it looks at the income of family members, the test cannot gauge how income compares to the expenditure of these family members, or whether they are inclined to help their relatives.

CHANGES TO CAREGIVING POSSIBILITIES

Given that many participants could not afford to hire a domestic worker or a professional caregiver, it is not surprising that several proposed alternative approaches to caregiving support. For example, some respondents suggested creating a network of part-time caregivers. Respondent97 proposed a database of caregivers that could be used in situations where a full-time caregiver was not required, such as if someone needed a caregiver to work only during specific hours, in case of an emergency, or in a situation in which the primary caregiver was unable to perform his or her tasks. Similarly, Respondent93 referred to her experience abroad, where she had caregivers who visited for a few hours per day. She explained that such a situation suited her better than having a live-in foreign domestic worker, as it allowed her to live independently and to maintain her privacy. Some respondents also suggested such an alternative during times when the full-time domestic worker took leave or to give the primary caregiver some respite.

Regardless of the model of caregiving support services, several respondents also mentioned the need for financial assistance with caregiving support. While many respondents relied upon family and friends to provide most of their caregiving, many claimed to prefer more formal assistance. For example, Respondent83 explained that getting help from a professional was preferable to relying on family or friends, as the latter approach made him feel like a burden. Respondent87 also expressed a preference for non-family caregivers, and suggested that it would be helpful to have volunteers visit

40 John Donaldson et. al., *Elderly Population in Singapore: Understanding social, physical and financial needs*, (Singapore: Lien Centre for Social Innovation, June 2015); Emma Glendinning, Catherine J. Smith and Mumtaz Md. Kadir, *Single-Parent Families in Singapore: Understanding the challenges of finances, housing and time poverty*, (Singapore, Lien Centre for Social Innovation, June 2015).

41 "Govt Awards Tender to Develop National IT System for Social Service Sector," *Asia One*, 30 May, 2014, <http://news.asiaone.com/news/singapore/govt-awards-tenderdevelop-national-it-system-social-service-sector>.

42 "Social Service Office Division," Ministry of Social and Family Development, <http://app.msf.gov.sg/About-MSF/Our-People/Divisions-at-MSF/Social-Development-and-Support/Social-Service-Office-Division>.

occasionally to do household tasks. There is also a need for training of caregivers for attending to those with intense needs.

EMPLOYMENT NEEDS

Unsurprisingly, a majority (26) of the 47 who wanted service improvements reported that they would like to have more assistance in the spheres of employment. These needs ranged from assistance in securing a job, to curbing discrimination in the workplace. For example, Respondent40 asked that “employers take on the same perspective as the government – to be less discriminating against the disabled.” Some respondents also expressed an interest in more opportunities for home-based jobs, and jobs with flexible hours.

Many respondents offered ways that sheltered employment could be improved. For example, some pointed out that the hourly rates should be higher – as discussed above in Section D on employment, the income from this type of employment tends to be quite low, and often cannot provide for people’s basic needs. Secondly, some respondents proposed that there should be an opportunity to acquire marketable skills via their employment. They argued that sheltered workshops only offer opportunities to perform basic, repetitive tasks and do not make their employees more hireable in the future, which should be one of the goals of employment assistance.

The “sheltered workshop” model offers a situation that is quite different from mainstream employment, and has fallen out of favour in many developed countries.⁴³ It has been argued that sheltered workshops only serve to further isolate people with disabilities, and often do not teach skills or provide any certification which would prepare them for integration into open employment.⁴⁴ However, many continue to face several challenges in mainstream employment, and unless it is made more inclusive, sheltered workshops may continue to be relevant. These workshops offer a safe space for many people with severe disabilities, and their absence would force them to stay at home experiencing further exclusion. Further, much more needs to be done to ensure fairer wages in the sheltered workshop context.

FINANCES

Participants’ financial worries were closely linked to the employment options available to them, and many reported wanting support with their finances in addition to employment support. Some respondents suggested specific solutions to their financial concerns. Respondent37 pointed out that more subsidies, or even free treatment at clinics for disease prevention, would be more cost-effective than paying for a cure.

Respondent98 suggested issuing a disability card which would cover medical expenses for the disabled, and would provide access to other support services without having to undergo means testing repeatedly. Such a system would be quite similar to the Pioneer Generation Package, which was introduced in Budget 2014.

ASSISTANCE WITH PHYSICAL AND EMOTIONAL WELL-BEING

For those who were seeking to address physical problems, and to improve their level of physical well-being, there were a few service suggestions. Some pointed to a need for more fitness centres, and for these to be made more physically accessible. Others suggested that there might be opportunities for fitness activities outside of fitness centres. A few respondents discussed their struggles to find and pay for massage therapy, and proposed that this might be made more accessible and less expensive. Finally, several respondents spoke of a need for assistance with socialising – some service that might allow them to venture out of their homes more frequently and to engage in more outdoor activities.

“SOCIETY MUST CHANGE”

Many respondents pointed to a desire for a change in the way society at large interacts with, treats and includes people with disabilities. That this desire was quite high on their list of suggestions – second only to better employment opportunities – should indicate its importance to our respondents, particularly given that employment affects most aspects of their lives. For our respondents, societal change includes better infrastructure to make public space more accessible to them, as well as a change in public perception about disability.

Regarding infrastructure, Respondent41 points out that “there are regulations for new buildings to be wheelchair-accessible, but old buildings leave much to be desired.” Similarly, many expressed a need for more ramp access, as well as priority queues for the disabled in places like banks. In cases where there is ramp access, respondents pointed to the need for gentler slopes and fewer turns. Some also suggested user-centred design practices: For example, Respondent89 wants “better thought-through facilities near my estate [home neighbourhood].The stairs have no railings, and the slope is too steep for the wheelchair ...” Several people also expressed the need for a motorised wheelchair, which would make their daily transportation much easier. Others mentioned more disabled restrooms, railings on staircases, accessible bus stops (i.e. either without steps or with slopes), and spaces at bus stops for the disabled.

43 “Recognizing Ability: The Skills & Productivity of Persons with Disabilities: Literature Review,” International Labour Organization, 2008.

44 Ibid.

**“
The stairs have no
railings, and the slope
is too steep for the
wheelchair...”**

Several respondents also mentioned the need to educate the public about disability rights. Some acknowledged the positive steps taken by the government to enable greater integration of people with disabilities into society, like disabled-friendly buses, but called on the government to do more. For example, Respondent75 argues that the government should educate Singaporeans about disability, so that people like him could be more integrated in society. Respondents expressed the wish

that more people would give way to them when necessary, and not stare openly at them, or in other ways make them feel like a spectacle. As Respondent94 noted, “Barrier-free and handicapped-friendly are different. I am very independent, but with the slope, it is just not easy. They should understand what independence is.”

**“
Don’t use handicapped
toilets and parking lots;
don’t block a slope for
a disabled person who
needs to pass.”**

Conclusion

This research has been conducted at an opportune time; the last few years have seen some major changes in Singapore's approach to social spending and support. Additionally, Singapore's signing and ratifying the UNCRPD are significant steps in the direction of affirming disabled people's rights to fundamental freedom and living in an inclusive society. While the Singapore government has been clear that these changes do not signal a move towards a welfare state, they are nonetheless important indications of a changing mindset. As these views continue to shift, and the government continues to look at the changing needs of various vulnerable populations, it is the ideal opportunity to look also at the unmet needs of people with disabilities.

The Enabling Masterplan 2012-2016 sets out clear objectives and benchmarks in the areas of education, employment and adult care. The findings in this report have demonstrated the multiple nuances of the pressures that people with disabilities face concerning care, education and employment. Additionally, the report highlights the intersections of various challenges such as accessibility, transportation, domestic or family arrangements and finances, in complex and dynamic ways, which influence the options and choices available to them to live an independent life with dignity.

One of the key findings of this research is that the environmental and social factors other than the physical disability play a disabling role in the experiences of the respondents. As discussed in previous sections, many facets of society need to change for PWDs to be less excluded. The government, SG Enable and VWOs have taken several steps towards this, but our respondents' experiences demonstrate that much more can be done. It also highlights the need for several sectors to collaborate towards a holistic system of care where PWDs' rights as individuals are respected. Many of our respondents highlighted the pressing need for greater public awareness. We recognise that it is imperative to shift the way society views them from being recipients of care, dependent on social

services and other caregivers, to independent individuals with a unique set of challenges facing them.

This is not something that can be fixed by small tweaks to the current system. Improving income rates for people with disabilities is a start but not all people with disabilities are employed. While any increase in finances would be welcomed, there are structural and societal issues related to equity and access that still need to be addressed in a comprehensive manner. Improved access to education through greater physical and transport accessibility; less expensive transportation options; and ensuring smoother transition to employment, can contribute to an independent life, where the disabled do not have to rely on family members and services so much.

As discussed in the report, the current system of informal, patchwork care networks, described in Section H, is simply not sustainable. People with disabilities, too often reliant on ageing parents, need solutions that take into account the care and financial needs of both, and the ways that these needs intersect in many places. A policy that assumes the family is the first line of support may not work for many who do not share amicable relationships within the household, thereby denying assistance to those who need support. Similarly, the intersections of caregiving and women's roles in it have serious repercussions on women's financial independence, especially as they grow older.

Further study in this area might include research into the frequency of these intersections (e.g. how many people with disabilities rely on elderly, or soon-to-be elderly, for informal support), and how support for such families might be integrated. Other research areas might include what level of need there is for part-time care, or temporary care, and how international models might be effectively adapted to meet the unique needs of Singapore's population. Whatever future research is undertaken, it should investigate possibilities for holistic care that will enable people with disabilities to engage in a more inclusive society.

About the publication

The publication concerns the unmet social needs of people with disabilities in Singapore. Researchers from the Lien Centre for Social Innovation, along with students from Singapore Management University, interviewed 100 people with disabilities over a period of several months. These in-depth interviews were designed to elicit detailed stories from the participants, which would inform our understanding of their needs and how services might be improved to better meet those needs.

The rich data collected from these interviews paints a picture of a community which has faced barriers in many spheres and stages of life. From major life issues like education and employment, to everyday concerns like transportation and negotiating crowds, the decisions of our interview participants are heavily circumscribed by their disabilities. This publication explores Singapore's commitment to becoming a more inclusive society, and offers in response the stories and suggestions from people with disabilities that might help to point the way towards this goal.

About the Lien Centre for Social Innovation

The Lien Centre for Social Innovation, a partnership between the Lien Foundation and Singapore Management University, was established in 2006 to advance the thinking and capability of the social sector. The Lien Centre contributes to a more equitable, inclusive and vibrant society by addressing social needs through innovative approaches. We drive socially innovative solutions by strengthening social sector organisations so that they become influential and effective partners with business and government. We also work at the intersection of the public, private and social sectors to catalyse social innovation.

SMU Change Lab is an action-oriented research and design programme within the Lien Centre for Social Innovation that investigates and responds to unmet social needs in Singapore.

All Lien Centre research is available for download from the Lien Centre website, at www.lcsi.smu.edu.sg

