

Caring for caregivers of persons with disabilities

Andrew Lim and Justin Lee
TODAY, 18 January 2019

According to the 2010 National Health Survey, approximately 210,000 people aged 18 to 69 provide regular care to family and friends.

This number is expected to increase with an ageing society and the government's push towards community-based care as healthcare demands rise.

There will be fewer family members to share the burden of care — for every citizen aged 65 and above, there are 4.4 citizens aged 20 to 64. This could drop to 2.4 by 2030.

Furthermore, one in two Singaporeans is expected to have some form of disability at 65.

Not all people with disabilities need constant care, but for those who do, their caregivers often embark on a lonely and challenging journey.

Unlike caring for a newborn child or an ageing parent, many are thrust into the role without warning, and find themselves groping in the dark.

On top of the physical demands of care, they have to acquire specialised knowledge and skills, additional financial resources, and reliable networks of support.

People with disabilities also face discrimination and stigma, the effects of which are felt by caregivers as well.

A 2014 study by the National Council of Social Service (NCSS) found that nearly half of caregivers of persons with disabilities experienced poor mental health. Four in 10 reported being psychologically distressed, with six in 10 feeling burdened by caregiving.

These findings highlight the need for attention and sensitivity to these caregivers' unique circumstances, and their urgent need for support.

Here, we outline three suggestions on caring for caregivers of people with disabilities.

First, caregiver support agencies should reach out proactively to caregivers, and emphasise the importance of taking care of themselves in the midst of caregiving.

The recent launch of the Caregivers Pod by SG Enable, Singapore's one-stop agency for disability-related resources, is a promising development that contributes to the work of social service agencies in supporting caregivers.

It opens up new possibilities for caregivers to participate in activities, receive training and access services and much-needed information.

Importantly, for these avenues to be accessible, the physical and emotional demands of caregiving have to be taken into consideration.

The Institute of Policy Studies facilitates a [Disability Community Network](#) to gather the views of stakeholders in the disability sector. At our last meeting on caregiver support, caregivers present shared the extent to which they have assimilated care work into the fabric of their lives.

For example, despite having a chance to rest, many caregivers who receive respite care – short-term relief from caregiving duties, such as through a nurse or substitute caregiver – express feelings of guilt for not attending to their loved ones. Instead of resting, they often end up fussing around the house.

It also takes a leap of faith for caregivers to entrust their loved ones to others — even those with caregiving experience — as there are many care needs that are specific to different individuals or hard to communicate.

Support should be made known early to caregivers by all existing touchpoints, from hospitals and diagnostic agencies to social service providers, especially when caregivers are grappling with their newfound roles.

It is vital that service providers offer help up front, build trust with caregivers through understanding their worries and establish self-care habits as an important means to sustainable caregiving.

Second, increase the availability of disability-specific courses on caregiving, including those for foreign domestic workers (FDWs) who are employed to assist caregivers.

The NCSS study found that contrary to popular belief, caregivers who employed FDWs required respite care.

One reason for this is that caregivers have had negative experiences with FDWs, who serve as deputy or primary caregivers on top of managing the household. Many FDWs are ill-equipped to take care of individuals with disabilities, and struggle with their tasks.

Their employers in turn live with the fear that FDWs would leave on short notice, leaving them short-handed.

The Humanitarian Organisation for Migration Economics (HOME) has noted that FDWs are themselves at risk of caregiver burnout, and need adequate preparation and training on caring for individuals with disabilities.

The government can boost the training capabilities of organisations such as HOME or the Foreign Domestic Worker Association for Social Support and Training. One way in which this could be done is to co-fund voluntary welfare organisations versed in the various disabilities to develop and provide caregiving courses.

This would help to address the lack of disability-specific courses covered under the ambit of the Caregivers Training and Foreign Domestic Worker Grants.

For caregivers who require financial support, a portion of the FDW levy could also be used to help defray course costs, agency fees or FDWs' monthly salaries.

Third, recognise and support caregivers' own initiatives to help one another.

Indeed, there are energetic caregivers who have been motivated and resourceful in creating their own forms of support.

Caregivers of children with autism have set up initiatives to cope with everyday demands, such as [NeuroDiverCity](#), a website which gathers and shares inclusive services and resources that can be reviewed by parents.

A group of parents also set up [Reunite Missing Children](#), a Facebook page that pools information on missing children with autism, which has led to these children being found more quickly.

Such initiatives are worth of the attention of social service providers, who can partner them to complement existing services, or point new caregivers in their direction. This is important as caregivers are often uninformed of new developments.

The government can also support these community-driven caregiver initiatives through providing technical support and consultancy, or awards in recognition of their efforts.

These initiatives demonstrate that caregivers can give of themselves as much as they would like to receive.

At some point in our lives, we will either be or will need a caregiver.

Let us not forget to care for our caregivers, as their well-being has a direct impact on the overall care given to those in need, and for the well-being of our society as a whole.

Andrew Lim is a research assistant and Justin Lee is a senior research fellow at the Institute of Policy Studies, National University of Singapore.