

Disability Community Network Roundtable III: Caregiver Support

By Andrew Lim

No matter how much we educate caregivers about the importance of rest, they will not rest. They will not let go and say, “You take my child. I’m going to sleep.” They will say, “This is my responsibility. I have to take care of my child, because nobody understands my child except me.”

— Sherena Loh, Executive Director of
Muscular Dystrophy Association (Singapore)

Caregiver Support was the theme of the third roundtable of the Disability Community Network (DCN)¹ on 29 November 2018. Held at and supported by the [Muscular Dystrophy Association \(Singapore\)](#) (MDAS), the roundtable was organised by Dr Justin Lee, Senior Research Fellow at the Institute of Policy Studies (IPS). Caregivers, members of voluntary welfare organisations and disability advocates came together to discuss the complexities of caregiving and ways to support caregivers of people with disabilities.

Supporting Caregivers of Persons with Muscular Dystrophy

Sherena Loh, Executive Director of MDAS, talked about the services that MDAS provides for caregivers of persons with muscular dystrophy,² including centre and home-based respite care³ services, training, and counselling.

MDAS also organises an annual, two-day Caregivers’ Retreat, which allows caregivers to meet and learn from counterparts, and take a break from caregiving while their children attend a separate Children’s Camp.

¹ The [Disability Community Network \(DCN\)](#) comprises voluntary groups, social enterprises and relevant parties that aim to make sense of, represent, and act on, the needs and gaps in the disability sector. It is part of a broader open collaboration initiative known as [socialcollab.sg](#). The DCN enables members to update one another on new developments and best practices, plug knowledge gaps collectively and collaborate on joint projects. Key deliverables include quarterly roundtables and closed-door discussions, and policy briefs as well as needs and gaps reports that represent members’ views on disability policy or key issues. The [first roundtable on Employment](#) was held in May, while the [second roundtable on Education](#) was held in August.

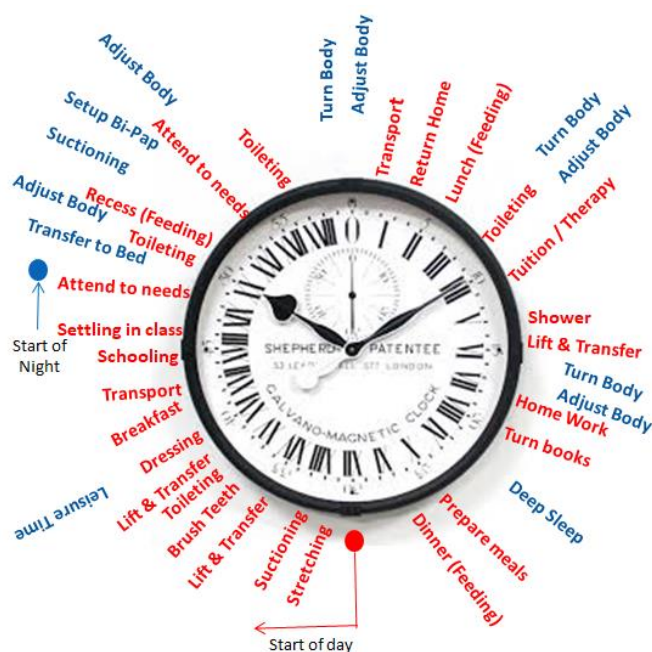
² While used as a general phrase to describe the progressive weakening of muscles, muscular dystrophy has many forms including Duchenne, Becker and facioscapulohumeral muscular dystrophy.

³ Short-term care relief for caregivers.

Throughout her presentation, Ms Loh emphasised the need to understand how much caregivers have assimilated round-the-clock caregiving into their own lives, usually at their own expense.

Despite having the chance to rest, caregivers who receive respite care often express feelings of guilt for not attending to their loved ones.

“During the time the children were away at our Children’s Camp, a parent came up to me. She felt very guilty. She told me that she had bought a pair of shoes for herself, and felt embarrassed. Another caregiver was surprised that she could go to bed at ten and wake up the next morning at eight, and felt as if she had forgotten her daughter,” Ms Loh said.



A representation of what caring for a person with muscular dystrophy looks like on a daily basis. Photo credit: Sherena Loh

Beyond self-responsibility, 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 not well-known or hard to communicate. Ms Loh described the common misconception that the skillset required to care for an elderly person is the same as that for a person with muscular dystrophy.

Caregivers of children with autism who were present agreed, citing instances where well-meaning individuals were unable to provide proper care and support. In their experience, it is because their children have vastly different needs along the autism spectrum — each child also has unique requirements that only parents would understand.

Trust Services for Persons With Special Needs

A common question for caregivers of children with special needs is, “How can I ensure that my children will be taken care of after I die?”

For some financial matters, there is the [Special Needs Trust Company \(SNTC\)](#), the only non-profit trust company in Singapore set up to provide trust services for persons with special needs.

“Our services are designed for low to middle income families, and is focused primarily on safeguarding monies rather than investment returns,” said Esther Tan, General Manager of SNTC.

Case managers work with families to develop a care plan that provides for the well-being of the person with disability in areas such as accommodation and daily living. SNTC will assist parents or caregivers to set up a Trust account to manage and disburse monies. Parents can also tap on the [Special Needs Savings Scheme](#), which allows them to set aside Central Provident Fund savings for the long term care of their children, upon the parent’s demise.



Ms Esther Tan (standing), General Manager of SNTC, sharing the scope of services that SNTC provides.

Giving Caregivers a Break by Teaching Children a Skill

It is rare to find programmes for autistic children and their caregivers that are fully volunteer-run, but One Child One Skill is one such exception.

The brainchild of Brenda Tan, a mother to an autistic son, the project matches tertiary students to homes to spend time with autistic individuals, and teach them a skill over eight one or one-and-a-half-hour sessions. Each session also serves as a source of respite care for parents.

One Child One Skill has two chapters in Ngee Ann Polytechnic and the National University of Singapore (NUS). Aw Pey Ling, a final-year student at NUS and Programme Coordinator of the NUS chapter, talked about her experiences with the initiative, which recently finished its

second run in October 2018. Caregivers who benefitted from it praised the project as a way for tertiary students to learn more about autism.

A vigorous debate ensued over the term “autistic children”. Some caregivers felt that the term was insensitive, citing traumatic experiences tied to its use as an insult. They felt that “persons with autism” was a more appropriate description, as it separates the medical diagnosis of autism from the personhood of the child.

Other caregivers disagreed, as the term “persons with autism” denies neurodiversity and the inextricability of autism from the person, and as their children take pride in identifying themselves as part of the autistic community.

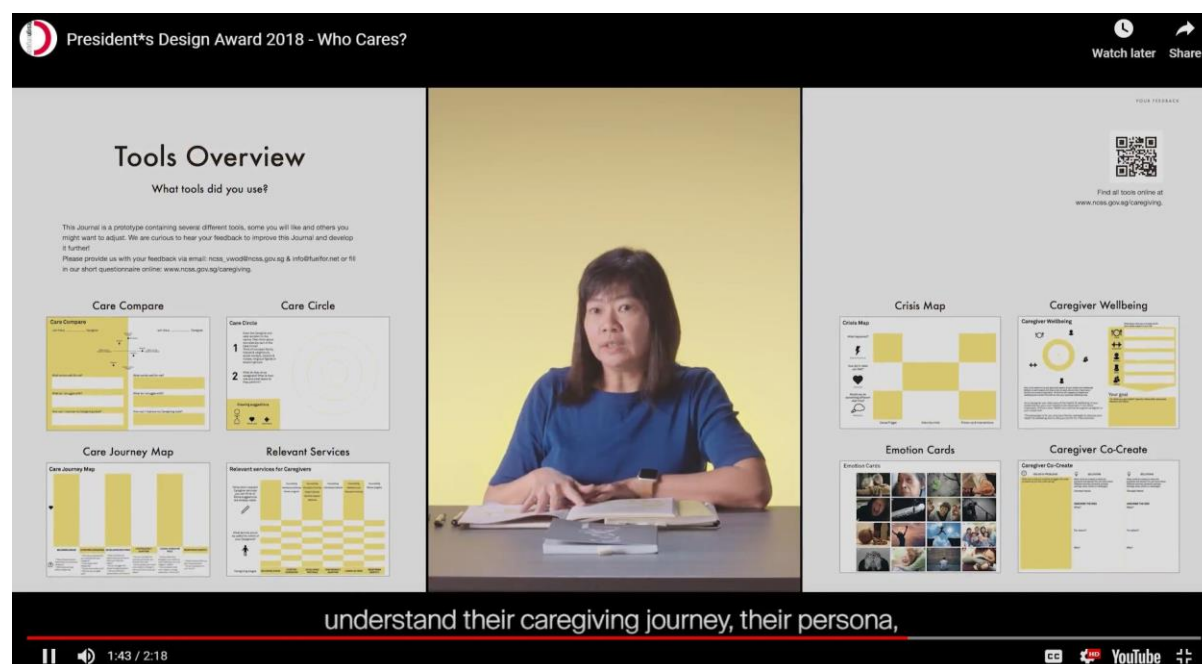
Ms Aw is keen to explore opening up other chapters of this initiative in other tertiary institutions, and welcomes schools to get in touch with her at awpeyling@u.nus.edu

Designing Solutions With the Caregiver in Mind

[Who Cares? Transforming the Caregiver Experience in Singapore](#) documents an award-winning project by the National Council of Social Service (NCSS) and design consultancy firm fuelfor, to understand the needs, values, hopes and fears of caregivers through a user centric design ethnography process.

Ms Stephanie Tay, Assistant Manager at the Pumpkin Lab, NCSS’s social innovation arm, talked about the genesis of the project and how its outputs are being taken forward.

NCSS is currently working with stakeholders such as Caregivers Alliance and the Institute of Mental Health, to further develop and refine the concepts gleaned. An actionable toolkit has also been developed for professionals working with caregivers.



A screenshot of a YouTube video showcasing some of the tools that service providers can use when working with caregivers. Photo credit: [DesignSingapore Council](#)

Agencies who would like to know more about the project can approach Ms Tay at stephanie_tay@ncss.gov.sg

Needs and Gaps in the Disability Caregiver Support Landscape

IPS Research Assistant Andrew Lim introduced wiki.socialcollab.sg, an open collaboration initiative working towards a ground-up understanding of social needs, gaps and solutions in Singapore.

He discussed a [Needs and Gaps Report on Caregiver Support](#) drawn from recent research studies, newspaper articles as well as inputs from community parties, identifying six broad categories of caregivers' needs:

- 1) Respite care
- 2) Physical health
- 3) Psychosocial wellness and support
- 4) Financial support
- 5) Future care planning
- 6) Caregiving skills and information

Several interesting but less known, volunteer-driven initiatives were raised, such as [NeuroDiverCitySG](#), a website which lists inclusive services and resources that can be reviewed by caregivers. A group of parents also established the Facebook page [Reunite Missing Children](#) to share information about autistic children who go missing, which has led to quicker re-discoveries.

Organisations and individuals interested to contribute their insights to these initiatives can contact Mr Lim at andrew.lim@nus.edu.sg.

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If you have comments or feedback, please email ips.update@nus.edu.sg



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