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'Who will look after him when I die?'

Amid renewed talk of greater support for caregivers of people with special needs, Channel NewsAsia meets two elderly mothers who chose to put their adult sons in disability hostels - albeit in differing circumstances.

By Justin Ong (/action/news/storiesby/storiesby/678458/storiesby.do?sortBy=latest&bylineId=2012300&pageNum=0) Posted 24 Dec 2016 09:07 Updated 27 Dec 2016 11:54



90-year-old Ng Ah Chun (left) with her son Tan Chye Teck, 50, who suffers from intellectual disability (Photo: Justin Ong)

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SINGAPORE: Only when Tan Chye Teck, 50, was found eating food scraps off public floors did it finally dawn on his mother, Ng Ah Chun. The 90-year-old, who can barely see due to deteriorating eyesight, was still recovering from both a fall and being bitten by a stray dog when she got the call from her son's instructor at the Movement for the Intellectually Disabled of Singapore (MINDS).

"Then I started to think," said Mdm Ng in Hokkien. "I already see my friends dying in their sleep. When it happens to me, who will look after him?"

The plight of elderly caregivers like Mdm Ng was highlighted earlier this week (Dec 20) as part of [proposals](http://www.channelnewsasia.com/news/singapore/new-5-year-roadmap-moots-more-help-for-caregivers-of-those-with/3380726.html) made to the Ministry of Social and Family Development (MSF) for a five-year plan to support people with disabilities.

Figures provided by MSF reveal some 16,000 people with disabilities who are aged 40 and above. Of these, around 1,200 are diagnosed with intellectual disability. Outside of their own homes, options for living arrangements include - in increasing magnitude of required care - community group homes, adult disability hostels and adult disability homes.

In early November, Mdm Ng placed her son - who is diagnosed with Global Developmental Delay - in a MINDS hostel. The facility offers training in job and life skills, and is where he goes back to on weekdays after clocking off work at MINDS' Idea Employment Development Centre. He spends his weekends with Mdm Ng at her two-room flat in Hougang.

"If our hostel residents deteriorate, we transfer them to the adult disability home as a last resort," said MINDS CEO Keh Eng Song. "But if they are capable and independent enough, we pull them out and consider them for the community group home."

Many caregivers fret over what will happen when they pass on, he acknowledged. "They would love to have a place reserved for their children, for peace of mind. We cannot say that we will reserve a place for them. But I always say: 'Don't worry, the Government is very much aware of this' and MSF's plan is for another three new adult disability homes in the next two years," said Mr Keh. "When the time comes, there will be a place."



Ng and her son on their 30-minute walk home from his hostel every weekend (Photo: Justin Ong)

PLANNING FOR THE EVENTUAL

For Mdm Ng, the time to live apart from her son came too sudden; too soon. "I didn't know how to think of such things," she said, when asked if she had ever made plans for his future after her death.

They have only had each other for a good part of her son's life. Mdm Ng - who is unmarried and has no other children - adopted him after he was abandoned on the steps of her neighbourhood church.

"He has always been very well-behaved," she said. "I just thought as long as he has a job and is well-behaved, that's good enough already."

It was a difficult, emotional decision to move him out of the house but Mdm Ng is confident her son is well taken care of. "I miss him, but there's no choice," she said. "I'm old already... We have to be separated."

Mdm Ng's story mirrors the reactive position taken by many caregivers, said Danny Loke, senior manager of special needs services at non-profit organisation TOUCH.

"Some caregivers think it's entirely their responsibility. They assume they can take care of their child forever, and haven't thought of the process after they pass on," he said. "They are very protective, and may not be as receptive. For some, it takes us many years to share with them that they need to plan for the future."

There was no such issue with 65-year-old retiree Lorna Wong and her husband, who in 2006 placed their autistic son Philip, now 35, at TOUCH Ubi Hostel.

"We knew that someday we will go and that was our main concern," said Mrs Wong. "It's important that he learns to be independent and on his own without his parents. We can't be with him forever, that's for sure."

MONEY MATTERS

Asked if a decade-long stay at a hostel had put a strain on the family financially, Mrs Wong said government subsidies helped keep monthly fees manageable at around S\$260 a month.

In care services, the means-test method is used to ensure patients from lower-income households receive more government subsidies than those from higher-income households.

“A lot of them fall into the category of almost 100 per cent government subsidies,” said Mr Keh of the patients at MINDS residential services. “But we charge a minimum of S\$50 monthly to make sure they still keep that bond with any relatives or siblings still around.”

“We also receive donations which we give out as financial assistance, over and above what the government is giving, in cases where nobody else can pay for them.”

As safeguards against adults with disabilities being left in the financial lurch when their caregivers pass on, MSF has in place two initiatives: The Special Needs Trusteeship Scheme (SNTC Trust) and Special Needs Savings Scheme (SNSS).

The former helps caregivers set aside sufficient funds in a trust and administers the funds to pay for care services upon the caregiver’s death. Although the trust fund requires S\$5,000 to start, financially disadvantaged caregivers can be fully or partially sponsored by SNTC depending on their circumstances, explained Esther Tan, general manager of SNTC Limited.

As of Nov 21, 427 SNTC trust accounts have been set up. Between 2014 to 2016, 375 caregivers have applied for SNSS. The latter allows caregivers to nominate their children with disabilities to receive monthly disbursements from their CPF after their death.



Mrs Wong says Philip wreaked havoc at the start of his hostel stay, playing pranks like throwing money down the rubbish chute (Photo: Justin Ong)

FINDING THEIR WAY

Another worry of parents and caregivers is that they might pass on before their children with disabilities learn how to integrate with society, said Mrs Wong.

“We don’t want them to be a nuisance to the public in future, so being educated properly is very important,” she said. “We want them to make themselves useful in some way, rather than be sent to an old folks’ home to wait to die.”

Mrs Wong said Philip, who is currently being trained for employment, has changed for the better over the 10 years spent at TOUCH Ubi Hostel.

“Every day he’s learning something. They teach him to look after himself; how to fold clothes, cook, mop the floor,” she said. “At home, he wouldn’t do any of those. I’m so happy that he’s behaving a lot better than when he was at home.”

Added Mrs Wong: “He used to show interest in females in a very different way that was not acceptable. TOUCH taught him how to behave in public. Now when we take him out, there’s no problem. He knows how to keep his hands to himself; not stare at women when he’s not supposed to; and not go near them and make them feel intimidated.”

“They don’t understand why he’s like that ... not many people can understand. A lot has been done for public awareness but a lot more needs to be done,” she said.

AGEING IN PLACE

A more immediate concern, according to both Mrs Wong and Mr Loke, is for adult disability residential services to extend their care beyond the age limit of 55.

"There is a gap," said Mr Loke. "If they live past 55, from adult disability services where do they go next?"

According to MSF, those who are still mobile and in good health can continue to stay on beyond 55.

But those whose conditions have deteriorated significantly will transit to nursing homes - which can provide medical support not available in residential facilities for persons with disabilities.

Mr Loke however pointed out that there are currently no nursing homes specifically catered for aged persons with disabilities.

For Mrs Wong, the ideal scenario would see Philip living out his golden years at TOUCH Ubi Hostel.





"We wish TOUCH or any other organisation can take a step further and look after those with disabilities all the way till old age," she said. "This structured environment is so important to them."

- CNA/jo

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