

Carers of Down syndrome sufferers seen to pay high price

Around one third of parents who are main carers of those with Down syndrome suffer physically and psychologically, a study has found.

The study, a joint effort last year by the Hong Kong Down Syndrome Association and the University of Hong Kong's department of social work and social administration, used set systems for checking self-esteem, well-being and depression.

The research found that 28 per cent of carers of Down syndrome patients suffer physical health difficulties and 27 percent psychological problems.

Of the 27 percent, 12 percent have slight anxiety and mood swings and the others mild, moderate and serious depression.

The survey drew on 231 parent-members of the association. More than half of their Down syndrome children are aged from 18-30, about 30 percent under 18 and the remainder from 31 to 51. Ninety percent of sufferers live with their families.

Association director Maggie Yeung Ying-mui said government officials have overlooked the needs of Down syndrome patients and their carers.

Most carers are middle-aged mothers who have quit careers to look after their children, she said.

Yeung urged the government to commit additional resources – such as providing subsidies – to carers to recognize their efforts.

Medical and transportation assistance for carers

would “give them more flexibility to allocate resources for their children,” Yeung said.

In February 2010, a motion to set up subsidies for carers of disabled people passed in the Legislative Council panel on welfare services. But no subsidies have been realized.

Yeung also called for a system of assigning case managers – nurses or social workers – to help Down syndrome patients as early as possible.

And she suggested the setting up of a clinic for Down syndrome patients above 18. They can no longer have regular check-ups in public health institutions and could be shifted to private clinics where doctors may not specialize in the condition.



How a carers' own health can suffer is revealed.

Official statistics show from 70,000 to 100,000 mentally disabled people in Hong Kong without a breakdown for Down syndrome. On that, Yeung's estimate is from 7,000 to 8,000 such patients.

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