

**A Presentation made at the Legislative Council on January 20 2015
On the Aging Challenges of People with Developmental Deficiency**

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Theme

We want to raise the concern about the aging issue of people with developmental deficiency! They need care, but they are often misunderstood

Sources of Information:

- Study done in Macau on the aging parents and their adult children with developmental deficiency 2011
- Case study done in Hong Kong on sheltered workshop workers and adults with Down Syndrome 2011 to 2012
- Relevant study done in Hong Kong on love and marriage issues of adults with developmental deficiency from 2009 to 2012

General Observations

- Much earlier than people would expected
- From international literature, the aging process may start at the age of 35 years among this group of people
- The more extreme cases could happened to those as young as 23 years old
- They have sight challenges
- Hearing challenges
- Orientation challenges
- General work performance challenge
- Less responsive to instructions
- Some one may have emotional issues
- Some other may have behavioral issues
- Self care abilities are declining as well e.g. swallowing ability
- Other issues such as skin, heart, bowel problems

They are Misunderstood

- Those challenges were often misinterpreted as so called work attitude problems, emotional spells, or behavioral challenges that were due to the decline of their sight, hearing and cognitive functioning
- It would be most unfair if these adults were then reprimanded, penalized, or having their choices or rewards limited
- Adults with developmental deficiency are often penalized for the alleged work attitude or behavioral problems.
- But they are just getting old.

The Care Provider

- Female family member is the major care provider;
- Less educated with less income (\$4000 to \$8000)
- Without much support from all levels
- Cognitive issues of the provider such as knowledge and skills in caring
- Emotional issues due to sacrificing personal choices for the caring work
- Stress management and mental health issue of the care provider is also an issue
- Aging of the care provider and decline of caring capabilities would make the caring work more difficult

Coping Strategies:

- They try to shoulder the sole responsibility all along
- A few adopted more drastic options such as committing suicides
- Some got organized to petition, lobby for more services provided by the government
- Some formed their own formal service organizations to render care

‘I see my own future when I read the news’ A 70 years old man’s response to a double suicide happened in Hong Kong when an old woman committed suicide by burning charcoal at home, killing herself and her son with developmental deficiency in Hong Kong

Other Coping:

- They arranged marriages to their adult children
- Finding a middle age man to the daughter or a young woman to the adult son with developmental deficiency
- But it does not work out well either.

The First Case:

- A young woman with developmental deficiency was arranged to marry a middle age man from the mainland was found abused often
- The man asked for a sum of cash from the parents and continued to ask for more
- He managed to leave the mainland because of this marriage
- But he abandoned the wife shortly after arrival.

The Second Case:

- Another young man with developmental deficiency was arranged to married a woman from the mainland by his parents
- They have a twin; both sons, but both are found disabled intellectually
- The wife left the family later
- Leaving the two babies and their father under the care of the grand parents, who thought the wife and these two sons could take care of the father later in the long term.

The Third Case:

- A man working in a sheltered workshop was arranged to marry a young girl from the mainland
- He felt good at the very beginning
- Then got stressful when the wife was pregnant
- More stressful when she left the family after giving birth to the kid.

It may work for a few though!

- However, some couples get married and are living reasonably happily
- Some of them got normal kids
- Some of them became grand parents later
- They live reasonably happily because they chose their own spouses and partners
- They chose their mates, not get married to someone arranged by their parents

Suggestions

- Formal residential arrangements for their children;
- Supported housing to the families with people with developmental deficiency
- Community care or support to these families with aging parents and aging adults with developmental deficiency
- Health assessment programme for persons with developmental deficiency at the age of 35 years.
- Close follow up to individuals plus a set up of a health data bank
- Provide with land, facilities and the right kind of manpower for their adult children
- The location of this kind of service must be accessible
- Training and quality of the staff would also be a concern
- More training for the care providers would be needed, especially those help them understand more about the changes of their children
- Support to the informal care providers
- Review on the Guardianship arrangements
- Supported Decision Making and the appointment of the Third Party Advocacy
- Formal services tend to provide care to single social group; i.e. either the old, or the disabled
- More studies on aging parents and disabled children must be launched

Thank you very much for your attention.

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