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Implementing a Proactive Seamless Case Management Mechanism**

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In September 2023, it was suspected that two brothers with intellectual disabilities in Sau Mau Ping Estate, Hong Kong, starved to death at home due to their mother’s four-month hospitalization and lack of care. This tragedy highlights the shortcomings of existing case management in Hong Kong. This article explores how a proactive seamless case management can help prevent a recurrence of tragedies for “hidden” individuals with intellectual disabilities.

Keywords: case management; intellectual disabilities; hidden needs; seamless and proactive

¹ Established in June 2017 by a cross-disciplinary research team, the Research Centre for Sustainable Hong Kong (CSHK) is an Applied Strategic Development Centre of City University of Hong Kong (CityU). CSHK conducts impactful applied research with the mission to facilitate and enhance collaborations among the academic, industrial and professional service sectors, the community and the government for sustainable development in Hong Kong and the Region. If you have any comments on this policy paper, email us at sushkhub@cityu.edu.hk.

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Introduction

A tragedy in Sau Mau Ping Estate reveals important gaps in current social services. The social safety net failed to play a “last resort” function when the brothers with intellectual disabilities and their mother did not actively seek help. In an aging population, the situation of “taking care of people with disabilities by the elderly” is getting more common, and family members who could have taken care of individuals with intellectual disabilities may be unable to fulfil the role due to declining ability. Currently institutional care hostels providing support for the disabled groups in Hong Kong are in acute short supply and the waiting time often takes several years, during which the carers’ ability to provide care may have significantly deteriorated due to old age and health issues. The needs of these individuals constitute a source of hidden needs for services in the community and potential points of crisis.

The current policy rationale for providing services to vulnerable communities, including individuals with intellectual disabilities, assumes that individuals in need should actively seek help. While this appears reasonable, it is important to remind that individuals with intellectual disabilities lack self-care ability and may not know how to seek help, let alone to secure it. Also, some families, influenced by traditional beliefs, are not accustomed to seeking help proactively. Therefore, relying on a service delivery model that depends on individuals in need to seek help proactively can easily create oversights in service provision. This is especially true in today’s society and the rapidly aging population, where high-risk communities require new risk-management approaches to prevent further tragedies.

In light of this, we propose the establishment of a proactive and seamless case management mechanism. A key feature of this mechanism is that it will provide a means to coordinate and integrate the services of different professionals and service providers in order to ensure the continuity of services and proactively identify high-risk cases for follow-up.

Proactively Identifying High-risk Cases

According to estimates by the Census and Statistics Department, the prevalence rate of individuals with intellectual disabilities in Hong Kong is between 1.0% and 1.2%, roughly equating to 77,000 to 90,000 persons. Although Hong Kong currently has daytime training and residential services suitable for individuals with intellectual disabilities, the supply falls short, considering the high demand. This is reflected in the long waiting list for the institutional care facilities. As Table 1 shows, the number of individuals waiting for hostels for moderately and severely mentally handicapped persons is almost equal to the total number of hostel places in Hong Kong. In other words, assuming no new supply, *all* existing occupants would have to move out before the demand from those currently on the waiting list can be met.

Table 1 Service quota and number of applications waitlisted in major services for persons with intellectual disabilities

| Types of services | Service quota ³ | Number of applications waitlisted ⁴ |
|---|----------------------------|--|
| Day Service and Training | | |
| Day Activity Centre | 5,808 | 1,169 |
| Sheltered Workshop | 5,399 | 2,160 |
| Integrated Vocational Rehabilitation Services Centre | 5,648 | |
| Residential Services | | |
| Small Group Home for Mildly Mentally Handicapped Children | 128 ⁵ | 113 |
| Hostel for Moderately Mentally Handicapped Persons | 2,800 | 2,750 |
| Hostel for Severely Mentally Handicapped Persons | 4,060 | 2,326 |

When individuals with intellectual disabilities are admitted to special schools, hostels, or other day services, they are guaranteed a certain level of care, notwithstanding frequent discussions on service quality deficits and delivery challenges. The risk of service oversight spikes when they fall outside the scope of these services,. Additionally, due to a lack of coordination, different professionals and service providers may not seamlessly render services for some individual cases.

The family involved in the tragic incident in Sau Mau Ping Estate received Comprehensive Social Security Assistance, and the two deceased brothers had had regular follow-up visits at the Psychiatric Specialist Outpatient Clinic of Kowloon East Cluster until 2018. Based on available information from various sources, the medical social worker at Kowloon Hospital, where their mother was admitted, had contacted a younger brother of the two brothers to discuss care arrangements after their mother’s discharge from hospital. They were informed that the two brothers would take care of their mother after her discharge. Additionally, the two brothers had, at an earlier time, visited the mother at the hospital, leading the hospital to surmise that they were capable of self-care (and taking care of the mother), and did not require further follow-up.

Although more details have to await further government investigations, an important issue has been revealed. Before her hospitalization, the mother had been, as a matter of practice, the “primary carer” for the two brothers. However, upon her imminent discharge from the hospital,

³ As at 31.12.2022; source: <https://www.legco.gov.hk/yr2023/chinese/panels/ws/papers/ws20230313cb2-183-3-c.pdf> and <https://www.legco.gov.hk/yr2023/chinese/panels/ws/papers/ws20230418cb2-302-3-c.pdf>

⁴ As at 30.06.2023; source: https://www.swd.gov.hk/storage/asset/section/341/en/Annex_II_Eng_20230630.pdf

⁵ Including services offered by Integrated Small Group Homes

in the planning of the hospital personnel, the two brothers became the “primary carers” for their mother. Normally we would expect this reversal of roles would raise alarm to the professional staff planning the post-discharge arrangement of the mother, if not for the two brothers. However, it did not. The reversal of roles is also technically in alignment with the definition provided by the Census and Statistics Department: a “primary carer” refers to the person who provides the longest hours of caring services during a week, regardless of whether s/he is unpaid (e.g., family member) or paid (e.g., foreign domestic helper and private nurse), or whether the ‘carers’ themselves are in need of care. These highlight the inadequacies of the current mechanism and infrastructures in dealing with high-risk communities.

It is imperative to establish a clearer set of guidelines to identify “primary carers” and high-risk cases. Professional personnels should be clearly assigned in new intervention mechanisms to systematically cater for circumstances that the identified primary carers lose their ability to provide care, whether due to hospitalization or accidents, or any significant deterioration of capacity. The core of this is to establish a seamless case management system.

Developing a Seamless Case Management Mechanism

Currently there are case managers in the 21 District Support Centres for Persons with Disabilities across Hong Kong. However, with limited human resources, their efficacy has been severely constrained. More importantly, the District Support Centres for Persons with Disabilities currently lack data on persons with disabilities in the respective districts. Without proactive outreach or referrals, these case managers are unable to provide support to hidden needs, and critical points of potential crisis, in the community. Barriers between different service and administrative systems have posed additional hurdles, for instance in the information gap between service providers. Establishing a seamless case management system is an important starting point. In particular, enabling better data sharing between different policy bureaus and between government and NGOs will allow different service points to share valuable case information to promote coordination and efficiency and eliminate oversights.

The Hospital Authority, the Social Welfare Department’s Social Security Field Unit, and the Education Bureau should work to integrate data on persons with intellectual disabilities, with the consent of relevant individuals (or their families), and then assign case managers from designated social service agencies to follow up. With the relevant data, case managers will proactively conduct assessments, identify high-risk cases, make appropriate referrals to service providers and seek resources as needed, and monitor the effectiveness of services provided. Case managers will facilitate information and knowledge sharing among service providers, reduce resource wastage, and bridge gaps of coordination.

The Social Welfare Department should review the scope and direction of services provided by the District Support Centres for Persons with Disabilities and actively provide support to

individuals/families in need. To effectively support families of individuals with disabilities and enhance their functioning, it is crucial to proactively identify and engage families with ‘hidden’ needs. Currently, in certain areas, the Housing Department collaborates with local Neighborhood Elderly Centers to share the addresses and number of households of elderly individuals living alone to enable the professional social workers in the latter to outreach and serve these elderlies. These collaborations dismantle the barriers between departments, ensuring that elderlies living alone receive care and support. This successful experience is worth promoting for assisting individuals with intellectual disabilities in the community. In addition, the government’s staffing and governance structures for handling the welfare of persons with intellectual disabilities should be reviewed accordingly, such as establishing a cross-bureaux coordinating committee that covers service organizations and other stakeholders.

Conclusion

It is challenging to identify “hidden cases”. Thus alongside with improved policy and services, it is important to step up mutual assistance and care for the needs of vulnerable groups in the community. However, to achieve a caring society, the rationale of welfare policy needs to shift from the current emphasis on “passive fragmentary service support” to “proactive seamless case management.”

In late September 2023, the Hong Kong government launched a new support hotline for carers, which received nearly 400 calls for help on the first day. This overwhelming response suggests that the depth of unmet demand – many carers in society do not receive sufficient support under the existing service model. The government is set to regularize the Scheme on Living Allowance for Low-income Carers of Persons with Disabilities and other measures, including an information gateway for carers to strengthen support to the carers. These are welcome improvements to the current services. In view of the escalating challenges of an aging society, it is high time to review the service model and implement a seamless case management system, and we may pilot the new system with persons with intellectual disabilities, given their acute vulnerability.