IDENTIFYING SUPPORT NEEDS OF ELDERLY CAREGIVERS OF CLIENTS WITH INTELLECTUAL DISABILITIES IN SUPPORTED EMPLOYMENT SERVICES IN SINGAPORE

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Abstract

The expanding population of elderly parents who continue to care for their child with intellectual disabilities well into old age is a growing concern (Hubert & Hollins, 2000). The research aims to assess the needs of elderly parents as caregivers and the perceived needs of their child with intellectual disabilities. Semi-structured interviews were undertaken with 10 caregivers aged 65 years and above. The interviews focused on identifying elderly caregivers' needs and the perceived needs of their child. Care plans were developed, in which caregivers' and clients' needs were prioritized. Elderly caregivers expressed support needs in several areas; social interaction and emotional support were common themes. When discussing their child's care plan, the need for their child to acquire Activities of Daily Living Skills and functional academics were some pertinent concerns. Other significant needs in their child's care plan include transitional planning, residential support and early intervention of medical issues. Identifying the support needs of elderly caregivers, and developing appropriate care plans are important to provide the necessary support as they age. Emphasis was also given in training clients to be independent, with the goal that they can be a support to their elderly parents.

Key words: Care Plans, Elderly Caregivers, Persons with Intellectual Disabilities, Needs Assessment

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Introduction

Often, persons with intellectual disabilities (PWIDs) is the focus of most research in the field. Nevertheless, the effects of intellectual disabilities (IDs) on caregivers are also pertinent. For adults with IDs, parents not only have to manage issues related to disability, but also problems associated with aging process of their child. This is a challenging process compounded with the fact that parents themselves are aging. This can make caregiving role highly stressful and lead to psychological, social, economic and health costs for parents.

Literature Review

Health issues faced by elderly caregivers of adults with IDs

In terms of general health, caregivers of PWIDIs appear to do worse than the general population (Grey, Totsika, & Hastings, 2017). Caregivers also complained of
somatic symptoms, such as long-term sleep deprivation, anxiety and headaches (Wei, Chu, Chen, Hsueh, Chang, Chang & Chou, 2012).

**Social and emotional issues faced by elderly caregivers of adults with IDs**

Pearlin, Menaghan, Lieberman, and Mullan (1981) related that an extended duration of caregiving can result in diminishing ability to cope with caregiving stresses. This results in an increased vulnerability to emotional stress and negative impacts on one’s health.

Wei et al. (2012) found that caregivers often expressed the need for their family, friends, and significant others to care about, trust, listen to, and appreciate them.

**Lack of availability of community resources for PWIDs**

Jokinen (2016) found residential services to be lacking, and are usually granted only under dire circumstances. Parents are concerned that there is no guarantee that their child has a place in a residential service (Jokinen, 2016). Some however shudder and procrastinate to think about future care. Similarly, in a study by Freedman, Krauss, and Seltzer (1997), less than half of 340 mothers aged 58-87 years old surveyed in the US had plans for the future care of their children, and 94.0% thought that their child would still be living with them within the next 2 years.

**The Singapore landscape of caregiving for adults with IDs by elderly parents**

Consistent with international literature, caregivers for PWIDs in Singapore face similar challenges in areas of health, social relationships, emotional well-being and lack of resources. Aging caregivers in the country have expressed health concerns such as asthma, knee problems, hypertension, and diabetes (Lee, 2015). Elderly parents in Singapore are concerned with the care of their child with IDs after they die. Ong (2016) found that they also fret over whether their child will have acquired the necessary skills to integrate into society. Many elderly parents hoped to plan for their child before they pass on and required assurance that there is residential support for their child in future.

The Movement for the Intellectually Disabled of Singapore (MINDS) Employment Development Centres (EDCs) cater to adults with IDs aged 18 years old and above, to develop their vocational skills and employability. They also aim to advance their development and well-being, empowering them to participate as fully as possible in society.

In 2013, a preliminary aging study conducted in MINDS EDCs found that 245 out of 984 clients were aged 40 years and above. In 5 years’ time, the figure is projected to increase to 507. According to Sinai, Bohnen and Strydom (2012), improvements in health and social service provision for PWIDs have enabled them to live longer. However, aging clients face accompanying physical and mental health challenges. Their increased lifespan also results in an expanding population of elderly parents who continue to provide care for them well into old age (Hubert & Hollins, 2000).

The Ministry of Social and Family Development (2009) defines elderly as individuals aged 65 years and
above, The preliminary aging study conducted revealed that 60.2% of elderly caregivers are caring for their children with IDs aged 40 years and above. Caregiving is the action of providing unpaid assistance to family members or others who have physical, psychological, or developmental needs, such as those in ill health or who are disabled (Drentea, 2007). A caregiver performs a certain range of tasks, including attending to physical, medical, emotional and financial needs of the care recipient (Singapore Silver Pages, 2013).

**Significance and objective of study**

Current literature both internationally and locally highlight the challenges faced by elderly caregivers who are still providing caregiving for their adult children with IDs as well as the need for more outreach and support to them. Internationally, aging populations and increasing demands for long-term services are influencing policymakers to consider policies that support families to avoid more costly institutional placements (Heller, Caldwell & Factor 2007). Furthermore, literature points to the pressing need for collaboration across the aging and disabilities service systems and the development of joint efforts rather than silo services (Heller et al., 2007). In this vein, this paper would be a seminal paper in Singapore in terms of looking at the needs of elderly caregivers of adults with IDs. The findings from this study would have implications in terms of informing policy in Singapore pertaining to support and services for elderly caregivers of adults with IDs.

To inform the type and extent of support that has to be provided for elderly caregivers of adults with IDs, it was necessary to identify areas of needs of caregivers through a caregiver outreach project. Needs were defined as financial needs, medical needs, informal social support, formal support, crisis management methods, future planning and other forms of support. There were two main research questions of this study: a) to identify the types of needs of elderly caregivers of adults with IDs and b) to develop care plans with the caregivers.

**Methodology**

**Participants**

10 elderly caregivers whose children attend MINDS EDCs took part in the research project. All participants were female, between the ages of 65 to 89 years old, with an average age of 73.2 years old. The caregivers were mothers, they provide the main caregiving. Their children were between the ages of 42 to 51 years old, with an average age of 46.9 years old, 6 of them were female (60.0%) while 4 of them were male (40.0%). 7 of them were Chinese (70.0%), 2 were Malay (20.0%) and 1 was Indian (10.0%). Convenience sampling was used to recruit caregivers, who also participated in the preliminary aging study.

**Materials and procedures**

Semi-structured interviews were conducted during home visits, and caregiver’s and client’s (i.e., adults with IDs) strengths and needs were identified. Care plans were developed with caregivers. The care plans included
clients’ and caregivers’ assessed needs, prioritized needs to be addressed and strategies for meeting the needs.

**Analysis of data**

Thematic analysis was conducted. The transcripts from the interviews were reviewed. The care plans were ranked based on level of urgency in caregivers’ and clients’ assessed needs. The assessed needs of 10 caregivers and clients were then grouped into 3 priority groups. Descriptive analysis of themes based on the 3 priority groups was done on frequency counts.

**Results**

**Caregivers’ assessed needs: First priority of needs**

30.0% of caregivers assessed reported Social Interaction and Emotional Support to be their first priority of needs. 30.0% of caregivers reported Retirement Planning as their first priority of needs. 20.0% needed support in Crisis Management. Financial support was reported as the highest priority of needs by 10.0% of caregivers while the remaining 10.0% reported that they had no areas of needs in which they required support.

**Caregivers’ assessed needs: Second priority of needs**

Among the second priority of assessed needs, 50.0% of caregivers indicated that Social Interaction and Emotional Support were important. 10.0% of caregivers reported that they needed support in Health and Medical Care. 10.0% indicated that they needed support in Retirement Planning. 30.0% of caregivers expressed that they did not have other needs.

**Caregivers’ assessed needs: Third priority of needs**

Among the third priority of assessed needs, 10.0% featured

**Table 1: Common themes identified in caregivers’ care plans**

<table>
<thead>
<tr>
<th>Priority of Assessed Needs</th>
<th>Category</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Social Interaction and Emotional Support</td>
<td>3</td>
<td>30.0%</td>
</tr>
<tr>
<td></td>
<td>Retirement Planning</td>
<td>3</td>
<td>30.0%</td>
</tr>
<tr>
<td></td>
<td>Crisis Management</td>
<td>2</td>
<td>20.0%</td>
</tr>
<tr>
<td></td>
<td>Financial Support</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Did not Indicate: Caregivers’ Needs are Taken Care of</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td>2</td>
<td>Social Interaction and Emotional Support</td>
<td>5</td>
<td>50.0%</td>
</tr>
<tr>
<td></td>
<td>Health and Medical Care</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Retirement Planning</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Did not Indicate: Caregivers had No Other Needs</td>
<td>3</td>
<td>30.0%</td>
</tr>
<tr>
<td>3</td>
<td>Health and Medical Care</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Social Interaction and Emotional Support</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Did not Indicate: Caregivers had No Other Needs</td>
<td>8</td>
<td>80.0%</td>
</tr>
</tbody>
</table>
of caregivers required Health and Medical Care, 10.0% assessed required Social Interaction and Emotional Support sometimes, 80.0% of caregivers expressed that they did not have other needs.

Descriptive analysis of themes based on the 3 priority groups were done on frequency counts, as reflected in table 1.

**Assessed needs of adults with IDs: First priority of needs**

Among the first priority of assessed needs, 30.0% of caregivers expressed that their child needed residential support in future, 30.0% of caregivers related that their child required Health and Medical Care, 20.0% of caregivers reported that they needed Financial Support for their child, 10.0% of caregivers felt that their child needed Behavioural Management, 10.0% were concerned over the ability of their child in performing Activity of Daily Living skills effectively.

**Assessed needs of adults with IDs: Second priority of needs**

Among the second priority of assessed needs, 10.0% of caregivers felt that their child did not have sufficient Social Interaction and Emotional Support, 30.0% of caregivers considered Residential Support for their child if they are unable to cope with caregiving, 10.0% of caregivers felt that their child needed Financial Support, Health and Medical Care and Behavioral Management respectively. 20.0% of caregivers reported that their children needed support in retraining of functional academics, 10.0% of caregiver related that siblings support is needed.

**Assessed needs of adults with IDs: Third priority of needs**

20.0% of caregiver assessed reported that their child needed Health and Medical Care support, while 10.0% reported that their child needed Behavioural

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**Table 2: Common themes identified in care plans of adults with IDs**

<table>
<thead>
<tr>
<th>Priority of Assessed Needs</th>
<th>Category</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Behavioural Management</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Residential Support</td>
<td>3</td>
<td>30.0%</td>
</tr>
<tr>
<td></td>
<td>Financial Support</td>
<td>2</td>
<td>20.0%</td>
</tr>
<tr>
<td></td>
<td>Others: Activities of Daily Living Skills</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Health and Medical Care</td>
<td>3</td>
<td>30.0%</td>
</tr>
<tr>
<td>2</td>
<td>Social Interaction and Emotional Support</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Financial Support</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Residential Support</td>
<td>3</td>
<td>30.0%</td>
</tr>
<tr>
<td></td>
<td>Others: Functional Academics</td>
<td>2</td>
<td>20.0%</td>
</tr>
<tr>
<td></td>
<td>Health and Medical Care</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Behavioural Management</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td></td>
<td>Others: Siblings Support</td>
<td>1</td>
<td>10.0%</td>
</tr>
<tr>
<td>3</td>
<td>Did not Indicate: Clients had No Other Needs</td>
<td>7</td>
<td>70.0%</td>
</tr>
<tr>
<td></td>
<td>Health and Medical Care</td>
<td>2</td>
<td>20.0%</td>
</tr>
<tr>
<td></td>
<td>Behavioural Management</td>
<td>1</td>
<td>10.0%</td>
</tr>
</tbody>
</table>
Management support as their third priority of needs. 70.9% of caregivers indicated that their children did not have other needs.

Descriptive analysis of themes based on the 3 priority groups was done on frequency counts, as reflected in table 2.

**Discussion**

**Meeting the social and emotional needs of the elderly caregiver**

The most common theme of assessed needs among elderly caregivers is Social Interaction and Emotional Support. According to National Institute of Aging (2017), there is a strong correlation between social interaction and health and well-being among elderly. As the elderly age, they value the connections they have with their relatives and like-minded friends. Hence, social isolation may have significant adverse effects on the elderly. The elderly should continue to develop good social emotional skills. Caregivers were encouraged to keep in close contact with relatives and like-minded friends so that they can continue to practice good social emotional skills. Although basic cognitive mechanisms may decline, such as recall or speed of processing, the elderly may still possess the emotion processing skills that allow them to function effectively (Blanchard-Fields, 2007).

According to Donaldson, Smith, Md, Kadir and Mudaliar (2015), in developing strategies for increasing social interaction of elderly in Singapore, the Ministry of Social and Family Development (MSF) supports the idea of ‘aging in place’. Singapore’s conceptualisation of aging in place has to do with developing strong social networks involving families and friends providing care, so that the elderly can continue to live in the community for as long as possible (Ministry of Social and Family Development, 2009). The Housing and Development Board has several schemes to enable the elderly to continue to live in their flats by encouraging their children and other family members to live close by. Such schemes include the Married Child Priority Scheme, Multi-Generation Living Scheme, Lease Buyback Scheme and Senior Priority Scheme (Housing and Development Board, 2017). Caregivers were encouraged to remain as occupant of their current flat for as long as possible so that they can maintain strong social networks with friends and loved ones in the community.

**Meeting the medical needs of adults with IDs**

As adults with IDs are increasingly aged, age-related health changes are evident (National Library of Medicine, 2007). One of the more common themes of assessed needs among adults with IDs is Health and Medical Care. The medical team (e.g., Medical Consultant, Occupational Therapist) at MINDS EDCs addressed some medical issues of adults with IDs. However, if the adults with IDs continue to regress medically, the services in MINDS EDCs may not be able to meet their needs. Therefore, referrals to step-down services are necessary. However, there may be limited placements and long waiting time for step-down services. To manage such situations, extra effort is required, for instance, in medical surveillance to ensure that interventions are rendered
to specific areas of decline at the earliest possible time (Hogg, Lucchino, Wang & Janick, 2000). In MINDS EDCs, adults with IDs are encouraged to participate in medical screening every 3 years. The medical screening is useful in identifying specific areas of decline, which will increase the probability of intervention at the earliest possible time. With quicker medical intervention, adults with IDs are able to maintain a better health status while waiting for the next service.

Meeting the long-term care needs of adults with IDs

Another common theme of assessed needs in the care plans of adults with IDs is the need for residential support. There are challenges in securing long-term residential support for adults with IDs as there are few disability homes in Singapore. It is however noted that respite services at disability homes are more readily available. Arrangements are made for adults with IDs to be placed on occasional respite care so that client can gain experiences of living away from home. Seow (2015) stated that a new residential home co-developed by MSF and non-profit organization St Andrew’s Autism Centre would be ready in 2018 for 200 PWIDs. This helps ease the worries of elderly caregivers, as more residential placements are available for adults with IDs.

2 out of 10 caregivers interviewed indicated that the siblings of adults with IDs have agreed to take over the caregiving responsibilities from their parents. Caregivers were encouraged to apply for deputyship application so that future care needs of their child can be managed by another sibling.

Meeting the needs of adults with IDs in acquiring Activities of Daily Living Skills and functional academics

Among the common themes of assessed needs in the care plans of adults with IDs: elderly caregivers are also concerned about their child who still required support in Activities of Daily Living skills and training in functional academics. Caregivers felt more assured that their child could live competently if these skills have been honed. According to Walker and Walker (1998, as cited in Hubert and Hollins, 2000), in households where there is an elderly parent and an adult child with mild or moderate learning disabilities, the nature of their relationship may gradually change over the years. Rather than the parent simply being the caregiver of their child, they may develop a mutually dependent partnership according to their respective needs and capabilities, and in some cases, the roles may even reverse. At MINDS EDCs, emphasis is given in working together with caregivers to maintain the independence of adults with IDs. This not only lessens caregiving burdens of elderly caregivers, but also with independent skills honed, it allows the adults with IDs to be a great support to their elderly parents by developing mutually dependent partnership.

Conclusion

According to Sinai, Bohnen and Strydom (2012), the improvements in health and social service provision for PWIDs have enabled them to live much longer than they
did in the past. This results in an expanding population of elderly parents who are continuing to care for their child well into old age (Hubert & Hollins, 2000). The research project recruited a total of 10 caregivers to conduct needs assessment and develop care plans, with the aim of providing caregiving support to elderly caregivers. One of the common themes of assessed needs among elderly caregivers is social interaction and emotional support. According to National Institute of Aging (2017), there is a strong correlation between social interaction and health and well-being among elderly. As elderly aged, they value the connection they have with their relatives and like-minded friends, social isolation may have significant adverse effects for the elderly. It was also noted that among the common themes of assessed needs in their child’s care plan, elderly caregivers are concerned about their adult children who still required support in Activities of Daily Living skills and training in functional academics. Caregivers felt more assured that their child with IDs could live competently if these skills have been honed. Emphasis is given in working together with caregivers to maintain the independence of adults with IDs. This not only lessens caregiving burdens of elderly caregivers, but also with independent skills honed, it allows the adults with IDs to be a great support to their elderly parents by developing mutually dependent partnership.

Reference


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