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**Community care for older adults  
with intellectual disabilities in Singapore**

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**ABSTRACT:** Persons with intellectual disabilities face unique challenges when entering the 3<sup>rd</sup> Age. This paper reflects on two community care options that enable such older adults to exercise choice and relatively independent living: the concept of professionally supported small-group living within mainstream housing estates; and day activity centers that promote quality of life for persons with intellectual disabilities. For such options to be optimised, we identify three essentials for public education.

## **Community care for older adults with intellectual disabilities in Singapore**

Unprecedented numbers of persons with intellectual disabilities (ID) are entering their 3<sup>rd</sup> Age this decade. Thus, there is a sense of urgency amongst local professionals as we plan and develop services and supports to meet the unique needs of these older persons with ID in Singapore. By presenting our paper at this Forum, we hope to further the conversation about community care options for older adults with ID. Our paper is a reflection on what it would take to enable the ideals of ageing in place to work for seniors with ID within the Singapore context.

We speak from the standpoints of three professionals who belong to the multidisciplinary team at the Movement for the Intellectually Disabled of Singapore (MINDS). MINDS is one of the oldest and largest organisations for persons with intellectual disabilities. It has four special education schools, six adult centers and one residential facility. We serve over 2,400 intellectually disabled persons and their families. Ageing persons with ID are a discernable group within our clientele.

As practitioners at MINDS, what excites us about planning for 3<sup>rd</sup> Age persons with ID is that the ideals have changed: mere survival is no more the life goal; and, it is not enough to focus on how to make persons with ID less of a burden to society. Instead, quality of life for seniors with ID has taken centre stage (Parmenter, 1992). Furthermore, quality of life is being defined increasingly by persons with ID themselves rather than by parents and service providers. Thus, in our paper, we also attempt to ground our ideas in what some of our clients are saying that they want in life.

Our guiding questions for this paper were: (i) In what ways does the experience of ageing differ for adults with ID from that of seniors with acquired impairments? (ii) Where are older adults with ID currently? (iii) Are there more desirable options for ageing in place for them?

### **The experience of ageing for PWIDs**

Older adults with ID do not form a homogenous group. When we refer to persons with intellectual disability (PWIDs), we include those with Down Syndrome, Autism Spectrum Disorder with ID, Idiopathic or Genetic "Pure" ID, Cerebral Palsy with resultant ID, ID with psychiatric conditions and so on. How each individual experiences ageing is affected by that individual's physical, sensory and cognitive conditions. While this is certainly true of seniors with acquired impairments, the difference is that our more severely disabled adults with ID at MINDS are not equipped with the intellectual and language skills to communicate to others their experience of ageing. At best, we make deductions based on direct observations and the words of a minority of our clientele. Nevertheless, whatever we are able to understand of the PWID's experience of ageing goes a long way in our efforts to develop need-based, client-centred programmes for them.

Seven key ways in which the challenge of ageing differs for many PWIDs from that of older adults who acquired impairments later in life are:

- i) The **early onset of ageing** phenomena is evident. For instance, features of premature ageing that are typically associated with Down Syndrome are progressive degenerative changes in memory and cognition that are usually associated with Alzheimer's Disease (Devenny et al, 2005). It has also been observed that the onset of health deterioration amongst PWIDs occurs around age of 40 (Lifshitz, Joav & Morad, 2008).
- ii) For many, multiple **pre-existing medical conditions** complicate adjustment to older adulthood. For instance, epilepsy, a frequent ailment in ID, can result in increased falls and secondary effects of anticonvulsant medications, such as bone demineralisation (Thorpe, 2003).
- iii) Ageing PWIDs have higher incidences of **physical problems** such as obesity which traces its roots to inactivity and an unbalanced diet (Melville, Hamilton, Hankey, Miller & Boyle, 2007). They may also have a higher propensity for mental illnesses such as dementia (Thorpe, 2003).
- iv) Typically, PWIDs are at a **financial disadvantage**. Their earning capacity during adulthood is far less than that of their nondisabled counterparts. This, coupled with their early onset of ageing which may compel an early retirement especially for those doing manual work, translates into paltry savings, if any, even for those who have worked in open employment. Even if their earnings were comparable to that of nondisabled adults, PWIDs would still need help in crafting viable financial plans for retirement.
- v) PWIDs are not necessarily able to learn and retain **self-coping skills** in circumventing the ageing issues they face. For instance, the non-ID senior with rheumatoid arthritis is usually able to adopt self-coping cognitive strategies to use bigger limb joints for task performance. The adult with ID may not understand this and may still continue to use painful small joints for the same task performance. In terms of socio-emotional adjustment, the PWID may have inadequate coping skills to deal with the deaths of older primary caregivers such as their parents.
- vi) For PWIDs who live with their families, **their primary caregiver(s)** tend to be their parents. When parents either pass away or become too frail, there may not always be siblings or other relatives to take over primary caregiving. Even for those willing to assume primary caregiver responsibilities, the burden of caring for an ageing PWID may be overwhelming.
- vii) The ageing PWID has a **limited social network** in comparison to the nondisabled older adult with friendships developed over a lifetime of full participation in society. The most isolated tend to be older PWIDs who have stayed home most of their lives because they did not attend schools and adult programmes. As for those who are

currently attending adult programmes, their friends tend to be fellow PWIDs. While this is not an issue in terms of enjoying their relationships, it is a handicap considering that such friendship networks are limited in their capacity to give mutual support to one another as they face 3<sup>rd</sup> Age challenges.

There are, of course, exceptions: persons with mild intellectual disabilities who are in good health, have strong social networks and even adequate savings. Nonetheless, they, too, may benefit from community care options specifically tailored for ageing persons with PWID.

This list of differences is from service providers' viewpoints, complete with our occupational inclination to view the shortcomings more readily, in our enthusiasm to help our ageing clients. There is clearly a knowledge gap when it comes to positive quality of life factors as perceived by PWIDs themselves. To deepen our professional understandings of the full experience of ageing for this diverse group, we need to listen harder to them. In that respect, commendable efforts include the focus groups conducted for Singapore's Enabling Masterplan 2007-2011 (see Ministry of Community Development, Youth and Sports, 2007).

### **Current programmes for older Persons with ID**

While there are numerous mainstream activities and programmes for seniors in Singapore, feedback from our clients and their caregivers has been that PWIDs are not always welcome to participate. In some instances, they are informed by the organizers that the programmes are not suitable for them.

Our review of residential and day centres exclusively for PWIDs shows that the current options of residential facilities and day centres (including vocational ones) have clients ranging from teenagers to the frail elderly. Inevitably, where group sizes are large, practitioners may tend to channel resources towards meeting programme goals tailored for emerging and young adults at the risk of neglecting 3<sup>rd</sup> Age PWIDs.

To get a sense of the numbers we are talking about, the following table shows how many of our current clients are – or will be – older adults. (We consider PWIDs who are 40 years old and above as older adults because of the early onset of ageing phenomena mentioned earlier.)

Table 1: Number of MINDS clients 40 years and above

Year	<sup>1</sup> TDCs	<sup>2</sup> EDCs	<sup>3</sup> MINDSville	Total No. of older PWIDs	Older PWIDs as a % of total adult enrolment (n=1200)
2008	16	149	69	234	19.5%
2012	33	245	77	355	29.6%

2016	41	364	86	491	40.9%

1. TDCs – Training & Development Centers (functional living-skills training facilities for adults)
2. EDCs – Employment & Development Centers (sheltered workshops )
3. MINDSville– Comprises of a home for destitute adults with ID, a hostel for some EDC adults with ID, and a children’s wing for some students from MINDS Schools.

By 2016, 40.9% of MINDS’ adult clientele would be in the 3<sup>rd</sup> Age range. There are also older adults at residential facilities and day centers of other agencies that serve adults with ID. Add to that the number who are staying at home and we have a sizeable number who need community care.

**More desirable options for older PWIDs**

As with any other clientele group, we recognise the value of providing a continuum of service options for older PWIDs. The ideal is to offer real choices and enable informed decision-making by PWIDs and their significant others.

In terms of residential arrangements, at one end of the continuum are adults living with their birth families. For this group, the caregivers need professional team support services to manage expectations about PWIDs who experiences early onset of ageing, and to cope with the increased burden of care at home. This would ensure that families have the continual support and, hence, capacity to include ageing PWIDs in their lives at home.

At the other end of the continuum are large residential facilities such as the MINDSville Residential Homes. But, for those who are able, a more ideal option would be long-term community care which dearly expounds the concept of quality of life (QOL) for PWIDs, including those who are ageing.

QOL has become one of the most essential outcomes of community care (Parmenter 1992; Schalock, 1997). QOL is associated with a number of productive shifts in service delivery principles and practices becoming increasingly attuned to creating personal choices and satisfaction, community membership and participation of individuals with disabilities (Felce, Lowe , Beecham & Hallam, 2000; Luckasson et al, 1992; Schalock, Bonham & Marchand, 2002). Furthermore, QOL lends itself to being a unifying concept for multidisciplinary service providers to assess the value of their programmes (Maes, Geeraert & Van de Bruel , 2000; Schalock, Bonham & Marchand , 2000).

One long-term community care option is supported living for PWIDs in the community. Independent living calls for a society that is inclusive and supportive of people who are different as well as the PWID being able to function at a cognitive level that is adequate to manage completely by oneself. Neither condition is typically met. An option that is very similar to this is that of a small group of adults with ID living together within the mainstream community but with

adequate supports from professionals. This model has proven to be both viable and desirable in several countries (Thia, 2007).

A community care service option of this nature would help to prepare PWIDs to cope with eventual ageing issues. The professional support could pre-empt being discharged from the group home because the PWID is unable to cope with the onset of, for example, Diabetes requiring diet monitoring and wound prevention. Professional guidance would also help PWIDs with financial planning within a community group home.

Current services supporting individual elderly living independently in the community include befriender services and home nursing care services. These are ingenious ways to safeguard the independent living preferences of seniors. The same principles of service provision and support would apply when planning for ageing PWID at community group homes.

For those who have satisfactory housing, long term community care options in the form of day centres, that are equipped to cater to the unique needs of older adults with ID, will ensure their continual engagement in communal life. Here, quality of life may be enhanced through, for instance, recreational therapy.

Ageing residents from MINDSville Residential Homes could enjoy access to such day programmes as well. In doing so, a real choice is created for these institution-based residents in terms of how they wish to spend their days.

Thus, community-based, long-term care initiatives such as these can make ageing in place a reality for older adults with ID here in Singapore.

### **Concluding thoughts**

To enable older adults with ID to age within communities of their choice, the public needs to realise that:

- (i) persons with ID have views and preferences which they are not always able to communicate in the same way as nondisabled older adults but they deserve to be heard nevertheless;
- (ii) long-term community care options of small-group homes within public housing and day centres tailored to their unique needs are viable options that would enable older adults with ID to experience optimal ageing in place; and
- (iii) when the larger community works in partnership with persons with ID and their families, there is potential for reciprocity within the relationships to the extent that community care may be mutually beneficial for all involved.

Despite not having any current alternatives, one of our MINDSville Residential Home clients said, “Other people think this is a jail, so we always tell them that it is a good place... play, eat and train.” Instead of a “jail”, let us all work together to make a variety of long-term community

options a reality for ageing PWIDs who wish to “play, eat and train” within communities of their choice.

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