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# Aging into a Disability

## INTRODUCTION

This report provides a general overview of challenges that persons aging into a disability may be confronted with. Although this is not a comprehensive review of the literature on aging into a disability, this paper aims to address the impact that acquiring a disability can have on a person and their social supports.

A disability can occur at any point in the life course and can cause unintended stress, strain and anxiety for an individual, as well as for their close family and friends. Previous studies have found that the perceptions and attitudes towards a disability change throughout an individual's life (Grassman et al., 2012). The age of acquisition can impact the social relations and activities youth and young adults participate in (Ostile et al., 2009) and differing perspectives on health and aging are seen throughout the life course. These authors found that there are different social, emotional and personal responses to disability depending on the age, the time the disability was acquired, and the different era that a person is born into. For this reason, the life course perspective provides a framework to study the effects of a disability throughout a person's life.

The life course perspective dictates that major life events, such as a disability, cannot be studied in isolation as people are always constructing and reconstructing the world that they live in (Edler, 1995). Untimely or unintended life events can disrupt the organization of an individual's path in life (Pearlin & McKean Skaff, 1996) and lead to disorder (Edler, 1995).

By studying the life course of individuals impacted with a disability, it enables the analysis of different attitudes and perceptions of disability throughout a person's life. In addition, it provides an opportunity to examine the impact that a disability can have for different ages and cohorts of people, as well as the impact of a disability on their social relations. By being able to study disability throughout the life course, services and programs can be evaluated and developed to aid in increasing the independence and quality of life of people living with a disability.

## AGING INTO A DISABILITY

As disabilities can occur at any point in the life course and they affect each age and cohort in a unique way, there are also similarities that exist. Persons with disabilities experience similar challenges no matter when they acquire a disability. These challenges include: uncertainty, lack of control, increased isolation, financial strain and affordable and accessible housing. Although there are many similarities in the challenges and supports that are required for disabilities that are acquired at any time throughout the life course, there are some unique elements to consider for disabilities that are commonly acquired later on in the life course. The population is living longer, including those with disabilities (both lifelong and acquired; Coyle & Mutchler, 2017). Due to the increased longevity, more and more older adults are finding themselves confronted with chronic conditions or functional limitations (Chernof, 2011).

The stress and strain of a disability are not only felt by the individuals impacted with them but it also has an impact on society. Persons with disabilities can have an increased strain on the medical system and social services (Chernof, 2011). However, there are supports and services that can be put in place

to help reduce the uncertainty and isolation a disability can have, as well as providing control. Many researchers have proposed different ways to improve and increase the quality of life of older adults with disabilities. These services can include exercise, educational and nutritional classes, personal and familial support, increased social awareness and suitable accommodations that are accessible and technologically advanced to provide support in a crisis situation.

## Wellness Centre

Some of the most common risk factors for developing a chronic condition include: physical inactivity, overweight/obesity, excess salt/sodium intake, raised blood pressure, elevated blood glucose levels and elevated fat in the blood (World Health Organization, 2017). In addition, studies have found that persons with disabilities such as arthritis are at a greater risk for developing diabetes and heart disease and emphasize the need for exercise and education programs to inform older adults about the virtues of a healthy lifestyle (Hootman et al., 2012). Promoting health and wellness of the entire population, as well as persons with disabilities, is important in preventing additional issues.

One study that looked at the development of a program that was based on health coaching through exercise and fitness classes, health and education promotion, and diet and disease management classes found a reduction in hospitalization rates for older adults (Holland, et al., 2003). This was done with exercise classes that take into consideration differing ability levels, creating health action plans to take control of managing any chronic condition they have, and self-management classes to promote nutrition and planning for the future. By promoting tenants of healthy living, it can reduce the impact and severity of a disability in an individual's life, promote healthy living and reduce social isolation.

### Exercise Classes

Numerous researchers (e.g., Brittle et al., 2008; Guralnik, et al., 2001; Holland, et al., 2003; Hootman et al., 2012; Logsdon et al., 2009; Reynolds & Silverstein, 2003; Smith, et al., 2011) emphasize the virtues of increased physical activity to reduce the impact, severity and occurrence of many disabilities that impact the aging population and a preventative measure for youth and adults to partake in throughout the life course. In fact, partaking in vigorous physical activity classes lowered the likelihood of experiencing the onset of a disability as a person ages by 27% (Reynolds & Silverstein, 2003) and can promote physical, cognitive and emotional health (Logsdon et al., 2009). On a general level, exercise and aerobic activities can reduce pain and increase functional ability for persons suffering from arthritis (Hootman, et al., 2012).

### Nutritional Classes

Many studies (e.g., Sharkey, 2004) discuss the link between low nutritional health and declines in physical health. By studying homebound older adults, Sharkey was able to determine that adults with poor food intake (i.e., low calcium, Vitamin D, magnesium, and phosphorus intake) had poor lower body performance. Sharkey recommends having appropriate programs for food and housing, increased availability of nutritional experts, increased collaboration between dietician and case managers, increased meals aimed at high risk individuals and the need to document the outcomes of nutritional programs for each person involved.

By educating older adults and the general population on nutrition, it can reduce the chances of developing chronic conditions later in life. Nutrition can be used as a tool to promote symptom management for conditions such as arthritis (Hootman et al., 2012), multiple sclerosis (Smith et al., 2011), as well as reducing the chances of developing comorbid health conditions such as diabetes.

### Educational Classes

In a public health study of arthritis in the United States, Hootman and colleagues (2012) stress the importance of educating patients with chronic conditions on self-management to become aware of

other ways to treat and care for their condition outside of medications. Educational classes are not only used to inform individuals of their disability but also to maintain active cognitive function. Maintaining the cognitive function of older adults can lower the risk of developing an instrumental activity of daily living disability by 6% (Reynolds & Silverstein, 2003). In addition, educational classes that maintain cognitive activity as one ages can reduce, delay, or slow the development of diseases such as dementia.

Recommendation: Given the importance of physical fitness and healthy eating on aging and disability, it is recommended that priority be given to wellness centres that incorporate nutrition and education class components in addition to the traditional exercise focus. Including these components will help increase awareness and understanding of living with and managing disabilities, helping to reduce the uncertainty and lack of control that can come with aging into a disability.

### Social Support

While absence of illness/disability and high cognitive, physical and mental functions were primarily the factors to identify successful aging, Kim and Park (2017) found that social and psychological functions are higher determinants of successful aging. This is also represented in domains for age-friendly cities identified by The World Health Organization (2007) that includes social determinants and personal determinants. For example, older adults with robust social networks experience a better quality of life (Lavasseur et al., 2004); however living in the community can present barriers to socializations (Depoy & Werrbach, 1996). Unfortunately, as a disability progresses the size of the social network often diminishes increasing the need for social supports to be facilitated through other means for both the person with a disability and their family. Diminished support can increase the stress and strain each person experiences.

Being able to provide social support to persons suffering from a disability and their family is fundamental in reducing isolation and uncertainty, as well as allowing individuals to become knowledgeable about their disability. Studies that have been conducted throughout the life course often highlight the importance of accessing support during the initial stages of diagnosis. Support can be offered through many means such as support groups, online discussion boards, support workers and family. The knowledge and information that a person can receive from a support group or online discussion board can provide them with insights into living day-to-day with their disabilities and medications (if required) (Josefsson, 2005). Having support groups like this helps to foster the development of friendships, which usually evolves past the commonality of the disability (Colineau & Paris, 2010). Hearing others' experiences and stories with a disability can often help individuals come to terms with their disability and foster an understanding that could not be provided in any other way than through peer support.

As a person ages, the primary source of support and care often comes from a spouse or a family member. The development of support systems are also needed for the caregiver of a person with a disability as they can experience stress, strain, burnout and guilt when caring for someone with a disability, often affecting the personal relationship (Boeije & Van Doorne-Huiskes, 2003; Stewart et al., 2006). Indeed, a caregiver's external supports diminish once they take on caregiver responsibilities for an older adult experiencing a disease like dementia. Stewart and colleagues (2006) found that by providing support to primary caregivers of Alzheimer's patients through telephone conversations with individuals who have also cared for an older adult with Alzheimer's they were able to develop better coping skills, learn new techniques for providing care, increase their competence and confidence in caring, and reduce their burden and loneliness by allowing them to have connections with someone that had gone through a similar situation. The support they received alleviated the stress and strain they were experiencing and allowed them to be better caregivers.

Recommendation: As social factors are determinants of successful aging and play a role in quality of life, it is important to consider and provide barrier-free opportunities for participation in social activities. Additionally, providing appropriate social service supports increases those opportunities for social networking with individuals in similar situations of aging into a disability.

Recommendation: Family caregiving creates social impacts for caregivers, decreasing their social networks and changing the social relationship with the person they are the caregiver for. This in turn, also has physical health implications with higher stress levels. Supports need to be available for family caregivers to help them maintain their networks and social relationship with the person (e.g., appropriate respite availability), as well as mental health programs to help manage the stress of caregiving.

### Community Life and the Built Environment

The lives and supports of persons with disabilities are influenced by the built environment the person must navigate, which can increase social isolation and reduce the control a person with a disability experiences. The community can present obstacles such as safety concerns, accessibility issues, lack of community services where housing is located and barriers to accessing and using transportation (Owen & Watters, 2006; Weeks & LeBlanc, 2010). This can be due in large part to the fact that accessible housing for persons with disabilities are normally zoned in areas that are less populated (Wolf- Branigin, 2006), or in inner cities (Owen and Watters, 2006).

Depending on the severity of the disability, the physical environment may hinder their quality of life. Levasseur and colleagues (2004) found that with increasing severity of disability, the physical environment can negatively impact a person's quality of life. However, they recommend that environmental interventions such as hand rails in the bathroom or mobility aids such as a cane may help reduce the barriers a person with a disability experiences and improve their quality of life. In addition, when a person with a disability is provided a choice in where they want to live in the community, many choose to live near public transit to allow them greater access to the community for work, social outings and school, which reduces the isolation they may experience and provides control in their functional abilities and future trajectories (Wolf-Branigin, 2006).

Recommendation: As the built environment can reduce access of the community and increase social isolation, older adults aging into a disability need programs available that provide assistance in implementing environmental interventions. Additionally, municipalities need to consider the built environment of their cities and consult with WHO's Age-Friendly Cities guidelines to assist them in creating cities that are accessible to persons aging into a disability.

### Housing

Historically, persons with disabilities were placed into an institutional setting, such as long-term care facilities, at an earlier age due to limited accessible housing options. That has begun and continues to change with the push to move older adult care into community living situations that allow older adults to live where they want and in a situation that can provide them with the best possible care. Care can be provided in the community setting through a variety of means such as informal care, support services, and even the use of assistive technology that supports older adults to age in place. By providing greater choice in the quality and accessibility of housing and support services, older adults with disabilities may be able to improve their quality of life, reduce their social isolation, and age in place. Below are some examples of models of care that have been implemented for older adults in communities throughout North America.

### Community Based Services and Supports

Day services or support services can provide support for older adults and delay a move into institutionalized care. The American system has implemented successful community care models for older adults such as Program of All-Inclusive Care for the Elderly (PACE), which provides medical and social care. In her review of successful community based in-home care models, Hansen (2008) describes PACE as including: primary care, specialty care, home care, hospital care, transportation, and meal preparation if needed.

Older adults enrolled in PACE have access to a physician, nurse, dietician, social worker, and occupational and physical therapist who create a care plan that is reviewed every 6 months (Hansen, 2008). PACE provides services for older adults on low income by combining payments from Medicare, Medicaid, and private pay for the services they provide. Not all services are available for low income older adults. As a general rule, the higher the income and more educated the individual, the more likely they are to use day services that will help facilitate aging in place by providing support in general areas of daily care such as meal preparation and household cleaning (Tang & Lee, 2010). This is a gap in services that needs to be addressed to ensure the same quality of life for all older adults no matter their income and education.

### Assisted Living Facilities and Supportive Housing

With a shift towards community living, there is an accompanying shift in the model of care towards a client-oriented approach. This approach aims to include the individual in the process of care and provide individualized and personalized service. A client-oriented care model has three elements: first, family members are involved in the care as representatives of the older adult; second, generalists and staff are hired to provide support instead of specialists in a care nursing home; and third, the physical environment needs to be safe, secure, and have the appropriate equipment (Chapman, Keating & Eales, 2003). Examples of client-oriented models are assisted living and supportive housing and are designed like a home to include: private bedrooms, bathrooms, and are located in neighborhoods.

When an older adult is living alone and suffering from a reduction in activities of daily living, moving into supportive housing can increase their quality of life (Newcomer et al., 2002). This can be seen as a way to maintain independence and choice that could not be provided for older adults in an institutional setting and provide support that they could not find on their own.

Several authors (Mashburn, 2006; Nolan & Mahar, 2000) have reviewed successful assisted living models, which include:

- ElderHealth in Seattle for older adults with severe mobility restrictions and dementia. These homes provide medical support, volunteer opportunities, and personalized care to increase the independence of their residents.
- The Air Force Villages Facilities. This is a care and research facility for older adults with dementia that has three phases of housing to provide care and support for older adults with dementia until the end of life.
- The Coming Home Initiative in Colorado, Arkansas, and Oregon. This initiative provides affordable and accessible homes to low income seniors.

What has made all of these initiatives successful is the fact that they incorporate local and national support. Many developed partnerships with local hospitals and care facilities in order to be able to provide health care and day services to older adults on a limited income. All reviews stated that the clients experienced greater independence, an increase in their quality of life, reduction in depression, and delayed entrance to nursing homes.

### Continuing Care Retirement Communities

A continuing care retirement community consists of both independent and assisted living models in one location to allow an individual to stay within the same community instead of being uprooted from familiar surroundings as they age and experience decreases in mobility and cognitive function. These communities can include: transportation, meals, fitness activities and health care services (Krout, Moen, Holmes, Oggins, & Bowen, 2002 in Silva-Smith, et al., 2011).

Continuing care communities have been linked with increased quality of life for older adults by allowing them to stay in a familiar environment and maintain social relations in the community throughout the transition from independent to institutionalized care. It should be noted that the cost of these options may be more than a large segment of the population aging into a disability can afford. Silva-Smith and colleagues (2011) state that the continuing care retirement community they studied is marketed towards the middle to high incomes brackets.

### Institutional Based Housing

In certain instances independent or community living is not possible for older adults with severe restrictions, nor is it a choice that some older adults want. Depoy and Werrbach (1996) found that among their participants who lived in an institutional setting, many did not desire the autonomy that those living in a supportive housing setting wanted and feared being isolated in the community. Most commonly, when older adults with disabilities move into an institutional setting it is based upon the severity of their disability, cognitive impairment, living alone, etc.

An example of a successful institutional housing facility is provided by Danes (2012) in her review of the Woodside Place Model. Danes (2012: 223) states that the Woodside Place model for older adults suffering from dementia includes the following principles:

- Respecting the dignity of each person.
- Acknowledging need for and providing privacy and community.
- Providing individualized care.
- Facilitating the opportunity for the creation of small groups to support relationship building.
- Encourage family and caregiver participation.

The location was adjacent to a regular seniors living organization and worked off of their administrative structure but provided individual rooms that could be personalized to how the individual and their family wanted it to be and had their own attached bath for privacy. The section of the seniors living organization dedicated to dementia care restricts the number of residents to 10 to 12 individuals, allowing for the development of friendships between fellow residents and their family. Woodside Place also operated a day service for older adults suffering from early stages of dementia who were still able to live independently in the community. This had two benefits; first, it allowed the older adults living in Woodside Place to develop friendships with other people outside of the care facility; second, the day services provided Woodside Place with future residents.

### Assistive Technology

Assistive technology can facilitate the opportunity to age in place. Assistive technology such as door sensors, monitoring equipment and touch and display phone systems can allow older adults to maintain their independence by providing them with increased control and empowerment (Milligan et al., 2011). The literature (Demiris & Hensel, 2009; Zwijsen et al., 2011; Rosenberg et al., 2012; Milligan et al., 2011) has also noted limitations to using assistive technology in the home that include an intrusion of privacy, lack of personal contact, creation of dependency on technology to perform day-

to-day tasks, stigmatizing effect due to visibility of aid and creating an institutionalized feeling in the home.

Researchers have noted the need to acquire consent and compliance before devices are installed in the home, and ensuring that the assistive technology is based on the individual's needs and wants (Demiris & Hensel, 2009). Older adults that have used assistive technology in the home refer to it as "friendly support" (Zwijsen et al., 2011), and rate the need for monitoring higher than the need for privacy (Demiris & Hensel, 2009).

Caregivers of older adults suffering from dementia appreciate the support that assistive technologies can provide as they feel that the increased safety of their family member overshadows the ethical dilemmas of using this technology in the home (Kinney & Kart, 2006). Many caregivers, however, did not want to become technological experts but wanted something that was simple and easy to use for both them and the person in their care that was incorporated into their daily habits (Rosenberg et al., 2012). Although there are benefits of using assistive technology for older adults such as increased monitoring and support if an accident were to occur, in certain instances the use of assistive technology can increase caregiver burden. Meiland and colleagues (2012) found that using the help function on the telephone can result in numerous calls to the caregiver thus increasing the burden they experience. Even with this added caring component, many felt the device was user friendly and a good tool to help support persons with mild dementia.

Recommendation: As living situations are important to the quality of life an individual experiences, it is necessary to provide choice in housing and support models. Collaboration between organizations needs to occur in order to provide these options in a cost effective manner to adults who are aging into a disability who have a low income. Use of assistive technology options can help to facilitate the choice to age in place.

## CONCLUSION

When specifically examining older adults aging into a disability, the literature provides options for services and supports that can be implemented to increase quality of life through reducing uncertainty, isolation and providing control, as well as a discussion of supports and services that can be provided in the home or through different housing models to access affordable and accessible housing to reduce the financial burden that aging into a disability can cause.

Summary of recommended areas to help improve quality of life for persons aging into a disability:

- Given the importance of physical fitness and healthy eating on aging and disability, it is recommended that priority be given to wellness centres that incorporate nutrition and education class components in addition to the traditional exercise focus. Including these components will help increase awareness and understanding of living with and managing disabilities, helping to reduce the uncertainty and lack of control that can come with aging into a disability.
- As social factors are determinants of successful aging and play a role in quality of life, it is important to consider and provide barrier-free opportunities for participation in social activities. Additionally, providing appropriate social service supports increases those opportunities for social networking with individuals in similar situations of aging into a disability.
- Family caregiving creates social impacts for caregivers, decreasing their social networks and changing the social relationship with the person they are the caregiver for. This in turn, also has physical health implications with higher stress levels. Supports need to available for family caregivers to help them maintain their networks and social relationship with the person (e.g.,

appropriate respite availability), as well as mental health programs to help manage the stress of caregiving.

- As the built environment can reduce access of the community and increase social isolation, older adults aging into a disability need programs available that provide assistance in implementing environmental interventions. Additionally, municipalities need to consider the built environment of their cities and consult with WHO's Age-Friendly Cities guidelines to assist them in creating cities that are accessible to persons aging into a disability.
- As living situations are important to the quality of life an individual experiences, it is necessary to provide choice in housing and support models. Collaboration between organizations needs to occur in order to provide these options in a cost effective manner to adults who are aging into a disability who have a low income. Use of assistive technology options can help to facilitate the choice to age in place.

## ABOUT VECOVA

Vecova Centre for Disability Services and Research (Vecova) is a leading edge registered and accredited non-profit charitable organization that has been meeting the lifelong and changing needs of persons with disabilities and the community-at-large since 1969 through our services, research, and enterprises.

Vecova's mission is:

> Building the capacity of persons with disabilities and enriching communities through leadership, innovation and collaboration.

Vecova's vision is that:

> Persons with disabilities are valued and integral members of society.
>
> - Persons with disabilities are **active** and **engaged** within the community.
> - Persons with disabilities are **included** and **embraced** within the community.
> - Persons with disabilities have the **highest attainable standards** of wellbeing.
> - Persons with disabilities are **resilient** and **enrich** the community.
> - Persons with disabilities are **safe** and **secure** within the community.

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