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The Middle Years and Beyond: Transitions and Families of Adults with Down Syndrome

Abstract

Normally expected transitions connect the various periods of life. Often these transitions are prompted by life events that require adaptation to a changed circumstance and may challenge both individual and family quality of life. Such transitions may be planful (proactive) or demand (reactive). Little, however, has been written about the nature of such transitions and how they specifically affect older-aged families of adults with Down syndrome. Such families are often predominate lifelong carers of adults with Down syndrome. Drawing on research and experience, the authors examined three transition points from a family perspective. Each of these points of change requires that people adapt and may lead to various outcomes, including at times outcomes that are unexpected, stressful, and challenging. The three points of transition examined include moving away from the parental home, changes occurring within a residential service (e.g., staff changes, relocations), and the reactions to the onset and course of dementia. Vignettes and quotes illustrate the complexities of these transitions and show that, even with planful management, often such transitions can go awry and produce unpredictable outcomes.

Worldwide population profiles indicate that life expectancy is increasing, particularly in the more affluent nations. This "longevity shift" has broad implications for the various segments of societies, including older individuals with disabilities, their family members, and the nature of programs within the aging and disability networks. As people continue to experience an extension in lifespan, theoretical models, practice interventions, and service delivery systems will need to be cognizant of the intersection between age, disability, and disease. Nowhere is this more relevant than to the expanding longevity of adults with Down syndrome (Percy, Summers, & Lovering, 2011).

Societies have deeply rooted notions about independence, self-reliance, family responsibilities, and of the role of government policies that may help shape support provided to individuals within a range of dependent populations, including people with disabilities and older persons, and their families. Among societies, the need for and availability of services and supports varies significantly. While many developed countries have produced diverse systems of social services in attempts to meet needs, other countries have few if any formal social services. Many countries and their governments are also struggling with economic woes while attempting to meet the demands of an aging population. In the meantime,

there is a growing recognition of the important role and place of family caregiving. Indeed, across the life span, family members predominately provide support for most people (young or old, with Down syndrome or other disabilities) (Braddock, Hemp, & Rizzolo, 2008). The individualized nature and context of familial caregiving (e.g., individual attributes, culture, location, and policies that support or impede family care), however, are necessary considerations in designing effective interventions to support families in their many and varied roles (Dilworth-Anderson, Hilliard, Williams, & Palmer, 2011).

Transitions are basically a movement through various life stages or notable life-course events that create some level of insecurity and require individuals to adapt (Golan, 1981, as cited in Ray, Bernard, & Phillips, 2009, p. 99). With increasing age, transitions can be expected to be marked by progressively more complex and socially significant life events that may include a change in residence, dealing with acute ill health or the onset of chronic conditions, and loss or death of family and friends. Processes associated with such transitions may be *planful* (proactive) or *demand* (reactive). Planful transitions often have more positive outcomes, since the stage for change has been set and the actors are prepared. Such transitions may include finding a new home, changing work, being drawn into a new circle of friends, and taking on new life responsibilities. Demand transitions may have unpredictable or adverse outcomes, since the transitional change is often precipitous or generally unexpected. Such transitions may include being injured or acquiring an unexpected disease or condition, having to relocate precipitously or without much warning, and the withdrawal of familiar supports.

All such transitional events impact individuals as well as their families – requiring adjustments to relationships, routines, and long held roles and responsibilities. Many older-aged adults and families apparently have a preference to “age in place” -- to maintain their current living arrangements for as long as possible (Jokinen, 2008). However, as individuals age, support may be required in order to maintain current living arrangements and families are often forced to consider alternative arrangements. While older-aged adults and their fami-

lies are a diverse group with varying needs, many manage such transition periods without seeking supports from formal services. However, supports obtained through social connections, individual self-care habits, and psycho-social resources can ease some transitions. Individuals and/or their families may, therefore, only come forward requesting assistance when a situation becomes problematic (Denton & Kusch, 2006). Despite the growing body of evidence on family caregiving, however, there is still much to learn about family dynamics and involvement in various periods of transition (e.g., who becomes involved, range of tasks, differing needs) (Gitlin & Wolff, 2011).

With respect to middle-aged and older adults with Down syndrome, life expectancy has increased substantially since the mid 1950s. At birth, the current cohort of middle-aged and older adults with Down syndrome (those in their fifties and older) was often not expected to survive much beyond early adulthood (Bittles & Glassen, 2004). Yet with advances in social and health care, many adults with Down syndrome are now living to ages previously unseen (Janicki, Dalton, Henderson, & Davidson, 1999; Percy et al., 2011). Although most do not attain the longevity averages for men and women in the general population, some middle-aged and older adults with Down syndrome may outlive their parents, siblings, or other close relatives. These adults were born in an era when professionals often suggested to parents that they institutionalize their sons or daughters, in part because community supports were limited at the time. Nonetheless, many parents chose to raise their child with Down syndrome within the family alongside their other children. Commonly, in those early years, families faced and endured negative public attitudes and opinions about Down syndrome. Seeking out mutual support and solutions to the dilemmas they faced, some of these families pioneered the first community services for persons with Down syndrome and other disabilities. Now, these same families are older-aged and experiencing inevitable age-related challenges and transitions.

Generally, the literature on transitions and adults with Down syndrome is somewhat divided. One focus has been on younger-aged adults transitioning from educational to adult

services and employment (see as examples Bouck, 2012; Pueschel, 2006), and another focus has been on the health problems or decline in health of older adults (e.g., Torr, Strydom, Patti, & Jokinen, 2010), or neuropathologies, (e.g., Janicki, Zendell, & DeHaven, 2010). Patti, Amble and Flory (2005) reported that adults with Down syndrome aged 50 to 59 experienced more life events compared to similarly aged adults with other intellectual disabilities. These life events included changes in living circumstance and/or day activity or program routines; death of, or separation from, a parent, friend, or roommate; and the onset of medical problems. Additionally, adults aging with Down syndrome were reportedly more likely to be in jeopardy of referral to a nursing home in later life – which raised the question what impact such relocations have on the individual (Patti, Amble, & Flory, 2010). Lunsy and Elserafi (2011) found that specific life events experienced by persons with intellectual disability were associated with increased hospital emergency department visits in reaction to a crisis. Furthermore, life events that prompt transitions likely have adverse impact on adults with intellectual disability and services may be able to control some events (e.g., staff changes and relocations), thereby mitigating emotional distress (Hulbert-Williams & Hastings, 2008).

Grant, Nolan and Keady (2003) acknowledged that individuals and families access various services throughout life and the impact of these transitions is not well understood. A dominant theme in the literature on older-aged families of adults with intellectual disability, including those with Down syndrome, is the need for parents (and families) to establish future plans. This is often viewed as a means to ease transitions and avoid the co-occurrence of two significant adverse life events (the death of a parent and need for relocation). While various planning models have been developed (see as examples Baxley, Janicki, McCallion, & Zendell, 2005; Bigby, 2004), commonly these planning processes highlight the needs of the adult who has a disability and promote a move from the family home prior to the incapacity of the main carer, usually the parent. Yet, although there is an underlying assumption that alternative living arrangements may be readily available, parents often lack information about housing options and few studies have reported fam-

ily perspectives on this type of move (Gilbert, Lankshear, & Petersen, 2008). The literature also points to a reluctance for older-aged parents to preplan for transitions or engage disability services (Bigby, 2004), yet planning processes seem to give little attention to the family as a whole with limited regard for the impact such plans have on other family members (Jokinen, 2008). Miettinen (2012) suggested that government policies and reduced social service funding have both direct and indirect influences on family decisions about the future. Limited access to housing alternatives and the quality of services provided seem to reinforce and prolong family caregiving potentially to the detriment of parents and their adult offspring.

It is within this context that we assess three transitions often encountered by older adults with Down syndrome and their families; some are typical and some are atypical. First, we consider the circumstances and perceptions of relocation when adults with Down syndrome move from the parental home where they have co-resided since birth. Next, we consider the transitions associated with changes in residential services (i.e., staff turnover and/or moving homes). Lastly, we consider transitions associated with the onset and progression of dementia. For each of these transitions, we highlight family carer perspectives. The vignettes¹ and quotes used illustrate circumstances suggestive of strategies that may ease transitions and better support both individuals and their families, and portray some unexpected outcomes even with parental or carer involvement.

Moving From the Parental Home

Parents and their adult sons or daughters with Down syndrome often wrestle with the decision as to whether to arrange separate living arrangements or continue co-residing. These decisions are influenced by a number of factors

1 The first two vignettes are drawn from published research (Jokinen, 2008) and the author extends appreciation to the families who participated in that research and their willingness to share their stories. The third vignette is drawn from a published article reflecting family perspectives (Hogan, 2010). All names used in the vignettes are pseudonyms.

including familial values and beliefs, finances, opportunities, parental retirement plans, and the health status of either the parent or their offspring. In the following discussion, family perceptions are highlighted regarding planned moves, and two examples of how plans may also change are considered.

Planned Moves

Vignette 1 offers a brief overview of the situation of Larry, a man with Down syndrome in his 40s (Jokinen, 2008). Larry's parents made plans for him to move out of the family home and were able to successfully realize their plans. They became actively engaged with a local provider organization so as to better understand the services available prior to the move and so that they could take advantage of a residential

option when one became available. An opening occurred in a supervised apartment living setting and the parents and Larry decided to take it. Larry moved to his new home, but all was not as smooth as it appeared on the surface. One of Larry's brothers confided that *"My mother, I don't know, hesitated for a good number of years because she [was a] typical mother, 'no one can look after my son as well as I can.' That was tough for her, for him to move out on his own. And she was over there every night of the week to make sure supper was cooked properly."* The daily visits by Larry's mother reportedly reduced over time as her comfort level grew with the staff support provided. Nonetheless, she and her husband maintained regular weekly support and visits. Parental support ended only with the deaths of both parents.

In other families, when parents do not initiate future residential plans for their adult son or daughter with whom they co-reside, siblings sometimes influence decisions and planning (Jokinen, 2008). One sibling, when reflecting on such a situation within her family, noted, *"We prompted my mom to start considering putting [my sister with Down syndrome] somewhere because my mom was getting [old]... she was 70 or something then, and we thought maybe that would be good and to do it while my mom was still alive so she could see that it worked."* The sister reported that after some further family conversations with her mother, she accepted the idea that her daughter with Down syndrome move. When an opportunity for a residential option -- in this case a small group home -- became available, the sister with Down syndrome, with the encouragement of her siblings, moved from her mother's home. Following the move, however, for unknown reasons the service provider reportedly was not supportive of family visits and this resulted in some tense relations between the family and service provider.

The reflections of yet another sibling regarding her brother's move away from the parental home also offers some insights into what might ease or hamper the transition of moving from the parental home (Hogan, 2010). The sibling noted that when her brother moved out of the home, he left behind a familiar neighbourhood as well as other residents and business owners with whom he had interacted over many years as a part of his daily routines. Consequently, after he moved into an agency group home, he experi-

Vignette #1: A siblings' story (Larry)

Dan and George are middle-aged brothers; both have their own families and work full time. Their brother, Larry, aged 41, has Down syndrome and requires significant support for activities of daily living and lives within a 24/7 residential service. Prior to and following his move out of the family home, both parents became actively involved on the agency's board of directors and were familiar with the services provided. After the move, Larry visited with his parents frequently and was included in family get-togethers. Both parents are now deceased and the brothers expressed appreciation for all that their parents had done in arranging Larry's living circumstance. They feel they now carry on with something their parents wanted. While, admittedly, the brothers do not see each other often, they involve Larry in family gatherings and support him as needed (e.g., with medical appointments). As to the future, the brothers would like things to remain as they now are. They are confident in the residential service and deal with issues as they arise.

enced a sense of loss and his absence in his old community was noted. This loss of involvement in one's neighbourhood and the inherent social relationships has generally received little, if any, attention, in the literature. The sister noted that once he relocated to the group home, her brother routinely returned home to spend weekends with his mother. In some respects, continued family contact is desirable and can ease transition while avoiding a sense of abandonment and abrupt separation from a valued community. On the other hand, such visits back to the family home may also inhibit being fully included in social activities with new housemates, slow down the development of new friendships, and hinder establishing an identity within the new neighbourhood. While routine familial support may increase, at least during the initial stages of a move, over time familial contact and support typically seems to settle into a new or adjusted pattern (Jokinen, 2008).

An individual's daily routines and responsibilities also likely differ between a family and new residential circumstance; whether this creates additional challenges needs to be considered. Brown and Brown (2003) referred to everyday routines that make life enjoyable, and to the need to balance established routines with new experiences that may or may not be adopted into daily life. Routines are an important aspect of both individual and family life (Jokinen, 2008; Knox & Bigby, 2007) and a fuller understanding of them can better ease transitions (Zisberg, Young, Schepp, & Zysberg, 2007). One lesson from these situations is that when necessity dictates a transition from the family home for an adult with Down syndrome, it should be individually tailored and designed to accommodate and manage those aspects of daily life that are important both to the individual making the move as well as the family.

Change in Plans

Despite having initiated plans for alternative living arrangements, sometimes an unexpected medical or similar significant crisis experienced by either the parent or adult with Down syndrome trumps a smooth transition. For example, a mother in her early 70s made an application for residential supports on behalf of her 40ish-aged daughter Julie who had Down syndrome (Jokinen, 2008). The mother, being proactive,

had registered her daughter with a local agency for residential options offered. After being on the wait list for almost ten years, an emergency relocation was required as the mother had been seriously injured and required hospitalization as well as an extended period of convalescence. The mother confided that *"...if I hadn't broken my hip, more than likely my daughter would still be at home."* While the emergency relocation turned into a permanent separate living arrangement for Julie, the transition was apparently fraught with disappointments, emotional upheaval, and challenges for both mother and daughter. Following emergency respite services, arrangements were made for Julie to move temporarily into a basement bedroom in a house rented by several adults with intellectual disability supported by a service provider. Julie had to adjust to both unfamiliar staff helping her and housemates whom she had never met. The mother reported that Julie's sleep patterns changed, she was waking and dressing in the middle of the night, and then later falling asleep on the living room couch. On the mother's first visit to her daughter's new residence when she was able to walk, she also found that the home's housekeeping standards did not meet her expectations (she found cobwebs, dirty carpets, soiled bedding, and the like). This issue was not fully resolved at that particular home, although housekeeping standards were better, at the mother's insistence, in a subsequent home Julie moved to and lived in. The lesson here is even though the mother was planful in getting her daughter on a list for a residence service – in preparation of the transition to moving from the parental home – she lost control of the process when she was injured and her daughter required emergency relocation. Although emergency relocations are not reportedly commonplace (Bigby, 2004; Jokinen, 2008), extensive residential wait lists across many jurisdictions that now exist may increase such situations and or place increased demands on other family members. Furthermore, standards within residential services seem to vary and parents as well as other family members may need to be prepared to advocate for reasonable living conditions.

Another example of a family situation offers a different circumstance that can alter planning for an alternative living option. Sometimes, parents and their offspring make decisions to live separately, only to have a medical crisis experienced by the adult with Down syn-

drome stymie plans and reinforce continued co-residency. One mother related that she had helped their daughter Helen to make plans to move away from the parental home (Jokinen, 2008). The mother related that: *“Well, there was a time when she wanted to go to an apartment on her own. And we were all for [it]. And of course that fall, when this was in the making, she got sick with diabetes. She just, she went into a coma and I got her to the hospital... So since then she hasn’t wanted to be anyway else but home.”* The mother related that Helen barely survived the medical crisis and the aftermath required adjusting to living with a chronic condition (in this case, brittle diabetes). The plans for Helen to live independently were abandoned. She continues living with her aging parents, now in their late 80s, with nominal services, and the family foresees her co-residing with her sister and brother-in-law in the future.

Older parents and their adult children with Down syndrome who make decisions to co-reside for as long as is possible need information and support to ensure that inevitable future transitions are well managed. The degree to which families have discussed matters and have made plans varies (Jokinen, 2008), yet this is a critical task and warrants serious conversation within the family. Cultural and ethnic beliefs also play a role in shaping attitudes towards aging and disability (Hogg, Lucchino, Wang, Janicki, & Group, 2000) and can influence an older-aged family’s caregiving experiences, expectations, and plans for the future. There is an urgent need to better understand transitions as they occur in conjunction with adult sibling co-resident arrangements. This information will aid family planning and help discern pros, cons, and pitfalls of future sibling co-residency in order to adequately plan for the needs of all family members (Jokinen, 2008).

Changes Occurring in Residential Services

Many older-aged families of adults with Down syndrome have extensive experience with disability services, often spanning decades, and with the changes that occur within a residential service that lead to transitions for both the adult with Down syndrome and the family. Some of these changes may be initiated by administrative

practices within agencies or the results of external forces (Hulbert-Williams & Hastings, 2008). Vignette 2 illustrates staff turnover and location moves within residential services as a period of transition for older-aged family members.

Changes in Staff

Disability organizations have long struggled with staff recruitment and retention (Hall & Hall, 2002). Numerous changes in direct care staff and their supervisors can disrupt relationships and impact the supports provided (Jokinen, 2008). In the second vignette, Mark’s mother remarked that over the years “hundreds of people” have come and gone with respect to providing supports for her son. She commented on the staff changes that had occurred and

Vignette #2: Even well-intended family help can go awry (Mark)

In one particular service, adults with intellectual disabilities rented accommodations and the agency provided support staff. Mark, a middle-age man with Down syndrome, had been living in a number of such accommodations since he left home. Mark’s mother, however, always took note of where Mark lived and under what conditions. She noticed that landlords often gave notice for tenants to move and rental premises were not always properly maintained. To overcome these problems, Mark’s mother purchased a duplex. She lived in one part of the house and her son along with three male housemates moved into the other half with part time support from residential staff. The men became well known by neighbours, local businesses and a church community in the area. With an organizational change, management decided to move the men across town to different rental homes. No discussions were apparently held with the families and the men lost contact with their neighbourhood friends and acquaintances.

the relations with various professionals, volunteers, and students that inevitably ended: *“Like their whole lives are up and down.... different people working with them coming into their lives for a short time and going.”* Sometimes, she said, people who moved on would try to keep in touch with Mark, but eventually these relations always dwindled away. Likewise, in the third vignette, Peter’s sister noted that her brother would become emotionally attached to “his staff” and generally they too would become attached to him. Often it was traumatic when staff turnover occurred and there was a limited understanding of why they had left. His family, like others, tried to help Peter stay connected to some of these people; however, most times, it was to no avail.

Staff changes impact family-service relations as well as the continuity and quality of supports. New staff often has a steep learning curve in getting to know an individual’s abilities, his or her history, and the nature of the family relations (Hogan, 2010). One mother noted, *“You know we’ve had 10 or 11 [supervisors] from the time that house opened... and I said [to the agency] I don’t know who I’m supposed to call... half the time I never even met the [supervisor]”* (Jokinen, 2008). Such changes in staff can lead to administrative problems, as well as personal difficulties for the person and their family. Often, with multiple staff turnover, there can be a generalized loss of knowledge about an individual, such as behavioural and medical history. This loss of knowledge may well contribute to medical disparities and aggravate health conditions, and possibly spur the onset of adjustment problems that are then characterized as “problematic” behaviours. These staffing difficulties may pose significant challenges for parents and other relatives involved with the adult with Down syndrome who face these transitions with trepidations, having experienced the consequences many times over.

Parents and adult siblings acknowledge staff turnover as a reality and this may reinforce the notion that families are the one constant in their relative’s life. Yet families may also have ideas to minimize the impact of staff turnover and should be consulted. For example, when staff changes are unavoidable, family members have suggested that agencies keep the number of staff moved around to a minimum and retain in place at least two or three key person-

nel who have worked with their relative. In doing so, familiar staff can ease the transition for the individual, their family, and the new staff coming onboard (Jokinen, 2008).

Relocations Within Residential Services

In the second vignette, Mark’s mother also raised several concerns about relocations within residential services. Although the solution to the situation Mark faced was functional and productive, in the end it was undermined by the decision of the agency (providing key supports) to change Mark’s living situation. Relocations within a residential service occur and are influenced by a number of factors, including whether the disability organization owns the residential properties or, as in this vignette, provides support staff for people who are renters. In the latter, long term security and upkeep of premises may depend upon landlords concerned with business opportunities who are not particularly sympathetic to disability or aging issues. Relocation may also be prompted by a restructuring of the organization, governmental budgeting vagaries, legislative initiatives, the dynamics of housemate relations, and changes in health status that require support beyond the capabilities of the current site. While some agencies have explicit policies, others lack guidelines about residential moves (Webber, Bowers, & McKenzie-Green, 2010). Nonetheless, as for anyone, changing residences and moving is a major life event and, when people move into a new home and new environment, adjustments are required by the individual, his or her family, staff, and those others residing at the new location.

In an attempt to reduce the likelihood of adverse relocations and to provide long term housing security, some parents have purchased homes where their sons or daughters and others might live with specialized supports. We recall another mother who suggested, *“It’s a sure way of having your child not moved every two or three years... if you want them closer to home, you can make an effort to find a house that you can buy in the locality where you want it.”* Referring to her own situation, she said of her daughter: *“She’s seven minutes away from me.”* However, the dual role responsibilities of parent and landlord are likely to be challenging and stressful. Decisions about who will live there, what the

home will offer in terms of furnishings and household goods, upkeep, and negotiations with a residential services provider to secure support are a few such details that need to be worked out (Jokinen, 2008). Further, while the option of purchasing a separate residence may be beyond the financial means of many families (Canada Mortgage and Housing Corporation, 2006, 2010), today's extensive wait times for residential services means that there is ever more demand on families to be self-reliant.

Changes Due to Onset and Progression of Dementia

Worldwide, the impact of age-related decline and the onset and progression of neuropathologies, such as Alzheimer disease and related dementias, on individuals and family carers is well recognized (World Health Organization, 2012). These events perhaps pose the last significant transition event in the lifespan, save for death. When adults with intellectual disability and their families are affected by this transition, it becomes more important that families and other carers are knowledgeable and prepared to deal with the challenges that are to come (Factor, Heller, & Janicki, 2012; National Task Group on Intellectual Disabilities and Dementia Practices, 2012). Many families of adults with Down syndrome are aware of the increased risk of Alzheimer disease associated with Down syndrome and, with increased age, there is a genuine concern about what this elevated risk poses for the future. In this final section, we discuss transitions occurring as a result of the onset and progression of dementia. Vignette 3, drawn from Hogan (2010), is illustrative of some of the issues faced by families with respect to this transition.

Parents and other family members face increasing challenges when their relative with intellectual disability evidences cognitive decline or behavioural change as a result of cognitive impairment or dementia. In one of few studies reporting family perspectives, Janicki, Zendell, and De Haven (2010) found many parents had a profound commitment and preference to keep and care for their son or daughter with Down syndrome at home. Their study noted that some parents also claimed that there was nowhere else for their son or daughter affected

by dementia to go, or that the family was resistant to moving him or her.

Decisions in response to progressive decline experienced by their sons or daughters were difficult and often considered to be influenced by a number of factors. Many parents report that they would seek help from a doctor or other clinician, look for personal care assistance, and or seek the support of a sibling. They

Vignette #3: Frustrations with a lack of knowledge and information (Peter)

Four years after the diagnosis of Alzheimer disease and 15 months before our brother Peter's death, he exhibited more dramatic changes in behaviour, personality and level of functioning. After exploring several nursing homes, we became convinced that he needed to stay with people who knew him. Safety risks for both him and the staff became a major factor and our only option was to request a transfer to a 12-person group home for severely handicapped and medically fragile people. The transition was very traumatic for our brother who was very confused and further agitated by the change. We needed to play a major role in the transition to make sure that the new staff bonded with him and to help them understand his needs. They had never had a resident with Alzheimer disease and, with little specific training on Alzheimer disease, needed a great deal of support and encouragement with difficult behaviours, such as changed sleep patterns. In hindsight, our family realized that none of us had fully understood the types of changes that would occur as Alzheimer disease progressed. We, as a family, were not mentally or emotionally prepared for what unfolded or for the rate of decline. Our brother was 49 years old when died of complications related to aspiration pneumonia seven months after the transition to the new group home.

suggested specific strategies to cope and manage things as they arose. These included acquiring support from an agency's treatment team, use of medications, and guidance from other carers who have had similar experience. When it came to finally facing the difficult decision of whether to seek help to arrange for another residential option, the parents noted that continued at-home care as dementia progressed was influenced by various factors. These factors included the medical needs of their offspring, the impact caregiving was having on their personal health, barriers in the home environment, safety issues, the level of support provided by other family members, and outside services available to meet needs. A critical aspect in the decision-making process was where the adult offspring would most likely go if he or she moved out of the family home. The carers speculated, if such a move was made, their son or daughter would likely go live with another family member or go to a group home while some indicated a preference for a long term care facility (i.e., a dementia care unit or nursing home). However, a prevailing theme was uncertainty; the parents were unsure where their son or daughter might end up, and this uncertainty was a major stressor with which they had to contend (Janicki et al., 2010).

In the situation of Peter, his sister noted that while her brother experienced progressive Alzheimer disease and remained living in his original group home, most staff at the home lacked training in understanding the progressive nature of the disease and in managing the new behaviours and diminishing abilities. Yet, at the same time, the staff remained committed to his care and tried hard to meet his needs. The lack of, and need for, staff training specific to dementia care is well recognized (National Task Group on Intellectual Disabilities and Dementia Practices, 2012; U.S. Department of Health and Human Services, 2012) as is often staff's hesitancy to relinquish supporting the person and have him or her move to another location (McCarron, McCallion, Fahey-McCarthy, Connaire, & Dunn-Lane, 2010). In Vignette 3, while additional support staff was scheduled, the ultimate challenge became the move to another group home during the later stages of Alzheimer disease (the home chosen was not a dementia-capable home, but one that provided for adults with severe impairments). While the intention was to have old and new staff work together for a planned transition, the

changeover was complicated and difficult for all concerned. Eventually, the new staff learned to care for Peter, both physically and emotionally and to communicate with his family – and the family reciprocated. As the sister reported, *"It was the best we could do."* In circumstances such as this, education, training, and communication are crucial to dispel misunderstandings about the move, the disease, its symptoms, and care requirements.

The lesson taken from these types of transition experiences is that catastrophic and other changes in function, whether cognitive or physical, pose special challenges for families. Dementia poses a realization for many parents that supportive caregiving will become more, and not less, pronounced and demanding with their own advancing age. Both the parents as they age and their offspring, as dementia takes its toll, will find continued care more taxing and force personal and family examination of transitions and compel conversation on what to do next. Older age will always necessitate transition planning, but the demands presented by catastrophic change such as that brought on by Alzheimer disease may lead to this conversation taking place sooner than anticipated.

Discussion

In this paper, we have attempted to address some particular lifespan transitions not previously raised and examined. Admittedly, this examination is cursory and based on summative and anecdotal data, but it does begin to examine family situations and perspectives as changes are encountered due to transitions that evolve organically or forced by crisis. We observed that this part of the lifespan potentially offers multiple examples of both planful and demand transitions.

We conclude that planful transitions are always less stressful and often lead to more positive and predictable outcomes and remain largely under parental and family control. Demand transitions, on the other hand, often lead to unpredictable outcomes and may result in control being relinquished to others outside the family. What we observed from our examination is that, even in situations where families observe natural pathways to decision-making and attempt to control and produce reliable outcomes, these may go awry due to factors

beyond their control. What we have learned from this exercise is that it is helpful to examine such transition situations, evaluate the options and alternatives, and follow in more detail those factors that facilitate or impede them.

What can also be gleaned from this exercise is the knowledge that the natural course of the lifespan can be interrupted by transitions. Sometimes these transitions are positive events and help lead to advantageous outcomes. Sometimes these transitions are calamitous and lead to adverse outcomes. Loss of staff has the potential to impact transitions and the level of care; communication or the lack thereof can interfere with the best made transition plans; and staff training needs to be examined as a possible means to ease transitions, especially in relation to diagnosis of a progressive condition. Families and those staff and organizations functioning in aid to families will be better equipped if they understand the dynamics inherent in these transitions and conjure up ways to constructively address them. Discussions of nuanced older age in the arena of intellectual disabilities are relatively new and, as of yet, a little explored frontier. With the extended and more normal longevity of adults with Down syndrome, any and all inquiries into this new frontier are most welcome and will be helpful in aiding families with planful transitions.

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