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Exploring Resiliency in Parents and Families of Adult Children: Living at Home with a Dual Diagnosis

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Introduction

This paper explores the coping abilities of parents of live-at-home adult children with both a developmental and mental health diagnosis, often referred to as a dual diagnosis (National Association of the Dually Diagnosed, 2011). We explore the literature on coping factors and social support for adults with a dual diagnosis and the coping abilities of parents caring for these adult children. Caring for a child with a developmental disability, especially in the present context of minimal public supports, challenges families significantly.

Families having adult children with both developmental disabilities and mental illnesses often experience poor social support (Esbensen, 2011; Minnes & Woodford, 2004; Saldaña et al., 2009; Unwin & Deb, 2011). Additionally, although some families report family cohesion similar to typical families, families with a disabled member may often experience more chaotic adaptability (Altiere & von Kluge, 2009) and lower levels of family expressive feelings (Heiman & Berger, 2008). Jones and Passey (2004) explain that “it is not enough for current services to provide professional support and consultation for such parents” (p. 43), but services must help parents “feel a greater sense of personal control” (p. 43). This means that service providers must understand how families adapt and cope in addition to understanding the challenges that they experience. Further research is needed to explain how this situation impacts families (Esbensen, 2011).

In addition to discussing historical influences regarding people with disabilities, dual diagnosis, and caregiving as an older adult with respect to the impact of stress, resilience, and social support, we also examine the effects of supports and resources

on caregiver feelings of resilience and perceived ability to cope with raising an adult child with a dual diagnosis.

Historical Influences

Foulks (2000) describes how mental illness was viewed in light of European and Middle Eastern traditions that associated mental illness with negative, ignorant thoughts, such as the work of the devil. As a result, communities often feared people with disabilities and considered their condition to be the work of the devil (Foulks). These beliefs linger in some areas today, where people perform exorcisms to attempt to relieve the symptoms of mental illness (Foulks). More passive individuals with disabilities were often housed in areas such as closets, cages and barns (Johnston, 2000). In the 1800s, asylums sprang up in Canada and the United States to care for those with mental illness and various disabilities and disorders such as alcohol addiction and depression (Foulks). More supportive viewpoints towards mental illness began to surface in the early 1900s when individuals began to advocate for the interests of persons with disabilities (Newfeldt, 2003). For example, Dortha Dix began campaigning in the United States to improve living conditions for individuals with mental illness (Greenstone, 1979). In Canada, Dr. Joseph Workman promoted proper clothing, exercise and nutrition, as well as medical and dental care for individuals with mental illness (Johnston, 2000). By the 1950s, the deinstitutionalization movement and the normalization principle gained ground in many Western countries, returning the care of those with mental illness to family members and communities (Miettinen, 2012). Society believed that parents should receive assistance in caring for their child

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diagnosed with a mental illness but upon adulthood the child should be promoted to live independently (Miettinen).

The 1970s, saw the closing of Canadian institutions for people with developmental disabilities, often leaving families in a position of independently trying to access health, mental health, support services, and create a welcoming school and social environment (Radford & Park, 2003).

Canada has used a decentralized approach to treating individuals with mental illness and developmental disabilities. Through the Canada Health Act, the federal government pays for healthcare, while each province and territory is responsible for the provision of healthcare (Canada Health Act, 1985; Gough & Morris, 2012). This approach has created treatment gaps due to differences in legislation; indeed the concept of dual diagnosis is not discussed in any provincial or territorial legislation, but it is mentioned in a written statement by the National Mental Health Commission in 2012 (Gough & Morris, 2012). Ontario has also enacted a variety of initiatives to assist individuals with disabilities by providing direct funds to families and individuals for disability services (Lunsky, Tint, Robinson, Gordyko, & Ouellette-Kuntz, 2014). These social policies have presented challenges for parents caring for adult children with disabilities, such as a lack of group homes and poor access to employment training and other important resources (Lunsky et al., 2014).

Defining and Living with a Dual Diagnosis

For the purpose of this study, we define dual diagnosis (DD) as the identification of co-occurring developmental and mental health disorders (National Association for the Dually Diagnosed, 2012). Terms such as intellectual disability and cognitive impairment are often used interchangeably with the term developmental disability (Ward, Nichols, & Freedman, 2010). Developmental disabilities have been defined as occurring before the age of 22 and affecting the individual's mobility, self-care, and communication abilities (Centers for Disease Control and Prevention, 2004; Ward, Nichols, & Freedman, 2010). In 2006, 14.3 percent of Canadians were identified

as having a disability, with 0.5 indicating they had a developmental disability (Statistics Canada, 2006). Additional statistics indicate that approximately 40 percent of individuals diagnosed with a developmental disability have received an additional mental health diagnosis (Cooper, Smiley, Morrison, Williamson, & Allan, 2007).

Research also shows that people with developmental disabilities are significantly more likely to develop "mental health problems or serious challenging behaviours" as they age (Weiss, 2012, p.67). Furthermore, numerous studies indicate that individuals diagnosed with developmental disabilities are at a higher risk of co-occurring physical and mental health concerns than the general population, leading to greater mortality rates (Kring, Greenberg, & Seltze, 2008; National Association for the Dually Diagnosed, Ontario Chapter, 2004). For example, Hollins, Attard, von Fraunhofer, McGuigan, and Sedgwick (1998) followed 2,000 individuals in the UK diagnosed with a developmental disability for eight years and discovered that their risk of mortality before the age of 50 was 58 times greater than the general population. Individuals with a DD face many barriers when required to access healthcare, and current services such as housing, formal and informal supports, financial assistance, and employment are felt to be insufficient in meeting their physical and mental health needs (National Association for the Dually Diagnosed, Ontario Chapter). Individuals with DD also have an increased risk for poverty and residing in substandard housing, and often have a lower degree of education than the general population (National Association for the Dually Diagnosed, Ontario Chapter). Research indicates that individuals with more significant disabilities participate less in social outings and employment instruction (Lunsky et al., 2014). Furthermore, individuals diagnosed with a developmental disability who receive few social support resources suffer depression at higher rates than those who get the necessary support (Lunsky, 2003). Therefore, individuals with DD and their families may need additional services that support their ability to participate fully in society and enjoy rich and rewarding lives

(National Association for the Dually Diagnosed, Ontario Chapter).

Older Caregivers

Given the increasing lifespans of individuals with disabilities (Chou, Lee, Lin, Kroger, and Chang 2009), the number of aging parents and guardians caring for adult offspring with developmental disabilities has also risen (Perkins & La-Martin, 2012). This reality places greater burdens on caregivers, who must plan for their child's care when they are no longer able to support them (Lunsky, Tint, Robinson, Gordeyko, & Ouellette-Kuntz, 2014). Chou et al. (2009) found that such parents were more likely to have a lower level of education, poorer health, and be single parents. Parental caregivers report a lower quality of life and fewer social supports (Chou et al., 2009). Women are more likely to be the primary caregivers of individuals with developmental disabilities and therefore exhibit more stressors from their role as caregiver than males (Chou et al., 2011). The difficulties experienced by caregivers of adults with a dual diagnosis depend on such factors as the degree of disability, the degree of supportive and financial services, and the knowledge and experience of the caregiver (Esbensen, 2011; Grant & Whittell, 2000; Lunsky et al., 2014).

Research suggests that when these caretaker parents obtain more knowledge and skills through experience and the passage of time, their positive coping skills and overall results improve (Grant & Whittell, 2000; Heiman, 2002). Older caregivers of individuals with intellectual disabilities do not report any greater levels of stress than younger caregivers of these individuals (Grant & Whittell), as older caregivers often undertake their roles in a more positive fashion than their younger equivalents (Chou et al., 2011).

Stress, Resilience and Social Support

Caregivers' ability to cope with their child's disability appears closely tied to interactions between risk factors, such as the impact of disability and protective factors which help families adapt (Olsson & Hwang, 2008). Family resilience suggests three critical protective factors: discussing their thoughts and concerns with others, positive interactions between caregivers, and obtaining

supports for all members of the household (Heiman, 2002). Family members of adults with DD report family unity similar to families without a member with a DD, but they often experience more difficulties with adaptation, fewer social supports, and fewer instances of family members expressing their emotions (Altiere & von Kluge, 2009; Heiman & Berger, 2008). Heiman (2002) believes that seeking support from psychologists, psychiatrists, social workers, support groups, and teachers can contribute to a family's resilience because actions to change their situation makes them feel better.

Studies of caregivers of children with intellectual disabilities have revealed that lower levels of hope in the caregiver and increased instances of behaviour problems in the child can be a predictor of maternal depression (Lloyd & Hastings, 2009). Studies have shown a strong correlation between a child's behavioral problems and maternal well-being; a greater level of reported behavioral problems in a child has been linked to lower levels of well-being in the mother (Kring, Greenberg, & Seltze, 2008). Kring, Greenberg, and Seltze found that mothers of individuals with ASD and psychiatric disorders reported greater amounts of stress and diminished parent-child relationships than mothers of children diagnosed solely with ASD. Additionally, poorer reported health and more frequent instances of asocial and unstable behavior in individuals diagnosed with ASD correlated to higher levels of distress in the mother (Kring, Greenberg, & Seltze).

Economic difficulties and caregiver health are strong forecasters of reduced well-being among caregivers of those with intellectual disabilities (Olsson & Hwang, 2008). And one can also assume that caregivers of individuals with health issues face additional responsibilities, such as attending frequent doctor visits and managing their child's medications. Families of children with ASD report being exposed to stressors, and the caregivers frequently describe increased levels of depression and anxiety, inability to engage in various activities, a strain in spousal relationships, and weakened physical health (Cappe, Wolff, Bobet, & Adrien, 2011; Kring, Greenberg, &

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Seltze, 2008; Shu, 2009).

Caregivers frequently mention social supports as effective coping devices for managing stress and improving their quality of life (Chou, Pu, Lee, Lin, & Kröger, 2009; King et al., 2003; Perkins & La-Martin, 2012). Stress has been described as a prominent feature of a caregiver's experience (Grant & Whittell, 2000; Heiman, 2002). Being a caregiver for an extensive period of time can be extremely stressful and "can lead to considerable psychological, social, economic, and health costs to the family caregivers" (Haley & Perkins, 2004, p. 24). As a result of their frequent role as the primary caregiver, mothers of children with intellectual disabilities report higher levels of stressors related to parenting than fathers (Gerstein, Crnic, Blacher, & Bak, 2009). The caregiver's perceived lack of supports and resources has also been found to be correlated with parenting stress (Spratt, Saylor, & Macias, 2007). Further research is needed to explore how families with a member with a DD differentially cope with care giving challenges (Esbensen, 2011; Jones & Passey, 2004; Unwin & Deb, 2011). The authors explore how social support affects parents' coping abilities and quality of life while caring for adult children with a dual diagnosis (DD).

Methodology

A practical qualitative research design provided a useful way to examine how family members cope when they live with and assist persons with a dual diagnosis. A qualitative method focuses on "understanding the meaning of human experience, from the subject's own frame of reference" (Holosko, 2006, p. 13). The qualitative approach shares the perspective that social meaning relates to social context and depends on how people in specific social settings subjectively interpret their experiences (Engel & Schutt, 2013). A qualitative approach employs practices such as: developing general research questions, selecting relevant site(s) and subjects, collecting relevant data, interpreting data, conceptualizing work, and writing up the findings (Creswell, 2014). A qualitative approach provides for the greatest learning possibilities to discover, understand, and gain insight in

the phenomenon being studied. This study uses qualitative face-to-face semi-structured family interviews and considers the following research questions:

1. What factors promote positive coping abilities in parents who care for live-at-home adult children with dual diagnosis?
2. How do parents with a live-at-home adult child with a dual diagnosis think they are coping?
3. How do parents with a live-at-home adult child with a dual diagnosis think they have coped?
4. What social support resources outside the family household are perceived to help families cope?
 - a. What formal supports help?
 - b. What informal supports help?
5. How does family coping influence families' quality of life for a member with a dual diagnosis?

The criteria for inclusion as study participants included parents of adults, 18 years of age and older (the age one is legally considered an adult in Ontario, Canada). For the study participants, we chose parents who assumed obligations essential to family life and who shared a common residence. Participants were recruited through posters/flyers at local community agencies and we relied on the snowball recruiting technique. Our goal of interviewing 15 families was based on qualitative research texts that generally recommend information collection via long interviews until the point of saturation with those who have experienced the target phenomenon (Creswell, 2014). Greater depth within interviews is stressed over breadth in a research approach that aims to interpret and understand the experience of study participants. Based on these suggestions, we concluded that 15 in-depth parent/guardian family interviews ensured the collection of sufficient data beyond the point of theoretical saturation, where no new insights are derived.

The research ethics boards of the University of Windsor and Southern Network of Specialized Care (a community agency) approved our re-

search. The interviews, which took place in family homes, gathered demographic information on the parents and the person with a dual diagnosis, such as age, role, education, socioeconomic status, diagnosis details, and severity of the disability. The semi-structured qualitative interview included the following questions as a guide:

- What has been your experience of your son or daughter's dual diagnosis?
- What positive experiences have you had with your adult child who has been diagnosed as having a dual diagnosis?
- What challenges have you experienced living with a person with a dual diagnosis?
- What formal supports (professional) have you experienced as helpful?
- What informal supports (family, friends, groups) have you experienced as helpful?
- What factors do you think contribute to positive experiences in your family?
- What factors do you think contribute to negative experiences in your family?

Analysis of the data involved reading all the transcribed descriptions and using Atlas.ti software (ATLAS.ti Scientific Software Development, 2002-2014) to code transcribed interviews and develop code categories. Extracting significant statements in a line-by-line process, the primary researcher assigned descriptive names or codes to identified units of words, sentences, and paragraphs, and sorted the codes into categories. The ease of creating, changing, and merging codes in the software program allowed us to find quotations, codes and categories quickly, and to make any changes efficiently. Next, the primary researcher compared category similarities and differences, and noted any connections (Creswell, 2014). Clustering statements into codes and categories of codes encouraged the process of making inferences and suggested themes that related to the research questions. The main themes do not simply reflect frequency codes or categories. Instead, the researchers sought to identify deeper underlying concepts.

Findings

Sixteen participants completed the demographic questionnaire (see Table 1). Eleven participants were female and four were male (one participant declined to answer the question). Most participants (10 of 16) were between ages 60 and 74. Six participants' incomes ranged between \$20,000 and \$80,000, while the other five had incomes beyond \$80,000. Six participants had high school degrees and an additional eight had university degrees or had taken graduate courses. Nine participants stated that their child resided in their home, and four participants said their child resided in their own separate dwelling. One adult child was living in a care facility. Nine participants reported that their child's disability was severe, and five reported a moderate disability. Ten participants reported that their child was male. Seven reported their child's age as 18 to 30 while another seven said their child's age was 31 to 45. Half of the participants had assistance with the care of their adult child.

The data from the audiotaped, transcribed interviews (see Table 2) was analyzed. Similar content was identified and organized into categories, and then developed into four themes. Table 2 shows the study categories and themes.

Theme A: Resilient Coping

Participants described positive experiences as outweighing the challenges they faced. As one participant stated, "I think he's slowly getting better." Coping methods included strategies that assisted participants in the raising of their children. The most frequently mentioned coping mechanism was using respite services. As one caregiver stated, "They've [respite services] been fantastic with helping me financially to get that little time to myself." Participants mentioned opportunities to take weekends alone and family vacations as ways to rejuvenate. As one caregiver remarked, "We would go to Florida every year and we would go to Disney World, and we spend a lot of time doing things like that...so for us that is our happy place." Another important coping method mentioned by caregivers was the opportunity to share their concerns and experiences.

Coping depended on participants' successful

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Table 1

Participants' Demographic Information (N=16)

Category	Options	# of Participants
Sex	Female	11 *
Age	45-59	4
	60-74	10
	75 or over	1 *
Income	Less than \$20,000	1
	\$20,000 to \$40,000	3
	\$60,000 to \$80,000	3
	Over \$80,000	5 *
Education	No high school degree	1
	High school degree	6
	University degree	5
	Graduate courses/degree	3 *
Residence of Child with DD	Reside in home	9
	Reside in own dwelling	4
	In care facility	1 **
Child Level of Disability	Moderate	5
	Severe	9 **
Sex of Child with DD	Female	5 *
Age of Child with DD	18 to 30	7
	31 to 45	7
	Over 45	1 *
Has assistance for caring for child with DD	Yes	8 *

* one participant declined to answer question

** two participants declined to answer question

efforts to acquire resources to help them support their children. They spoke positively about formal supports, services provided by agencies or organizations, such as respite services, day programs, and medical agencies. As one participant emphasized, “Her life has been enhanced by the experienced caregivers.” Four caregivers mentioned that workers from their child’s school or day program worked collaboratively with them by keeping them informed of their child’s progress and any new developments. Many caregivers also used multiple forms of medical support. Two caregivers said they were required to hospitalize their child to receive treatment. One caregiver stated that they “...

took him to a hospital two or three times.” And one participant stated, “Our pediatrician was so good to [our daughter]” while another revealed, “He goes to a psychologist. He takes medication...without it he is just so out of control.”

Informal supports, provided by family and friends, were a significant factor in resilient coping. Four participants found their child’s siblings supportive. As one participant elaborated, “...he looks after a lot of the paper work that needs to be filled out or his taxes...we talk to him about our problems, and it’s very helpful that way as far as moral support.” However, three caregivers mentioned that their children frequently experienced

Table 2

Codes, Categories, and Themes Found From Interviews

Themes	Categories	Codes
A. Resilient Coping	1. Rewarding Experiences	Positive Experiences Coping Methods
	2. Accessing Social Support	Formal Supports Informal Supports
B. Noting the Adult Child’s Interests and Interactions	3. Child’s Interests and Interactions with the Parent	Child’s Interests Interaction with Child Child’s Personal Relationships
	4. Education and Work Experiences	School Work
C. Struggling to Stay Hopeful	5. Difficult Experiences	Challenging Experiences Finances
	6. Looking to the Future	Caregiver Fears Future Goals
D. Coping with Stigma	7. Diagnoses	Testing Disability Perceptions
	8. Educating Society	Disability Education Thoughts on Research

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conflict with each other. One caregiver revealed, "My other son calls him a retard...He never comes here, he never takes [my son] any place or anything like that." Finally, two caregivers stated that the father of their child does not provide any assistance, with one caregiver disclosing, "His father was no help to me whatsoever; because when [our son] was four years old we divorced. He had nothing to do with him: birthdays, nothing..." Caregivers also described challenges in obtaining support from extended family members, with geographical location noted as an obstacle. However, participants often received much needed support from other parents of children with disabilities. One caregiver stated, "We got to know the families that had children with disabilities...It was just [that] we were thrown together because of a common cause." Another caregiver suggested... "I would not have been so happy if I hadn't met them. [I] am still in touch with these people...I feel very fortunate to know these people."

Theme B: Noting the Adult Child's Interests and Interactions

Participants frequently discussed their child's interests and interactions; for example, their child's knowledge of technology. Reflectively, one caregiver stated, "She has a wonderful attribute, she is very good with computers and she is really good with iPads and all of those wonderful things and I am not." Other participants mentioned their child's interest in singing and participating in a band. Dancing was another popular hobby, mentioned by two caregivers. When discussing their interaction with their child, two caregivers mentioned the importance of persistence and patience with their children's outbursts. In discussing personal relationships their child developed with others, one caregiver spoke about their child's close relationship with their respite workers, stating, "She loves going out with them and doing things with them, and I think you have to understand for some of the children these workers are friends. She doesn't have...friends to go out with to the movies, to the mall, chat on the phone with. She doesn't have that. Her friendships are the [respite] workers..."

When discussing their child's experiences in the education system, five caregivers stated that their child attended an integrated school with the sup-

port of a worker. One caregiver revealed, "When he was four, he was one of the first to go to [a] regular school system...with a worker in class... They had a buddy system where kids in different grades would look after him during recess. They loved him at the school." Three caregivers revealed that their child was bullied in school. One caregiver discussed her child's experiences, revealing, "Other kids in the class would bother him." Another caregiver said, "The school system failed him...He was continually harassed and hurt at school." In some instances, participants' children enrolled in a university, as mentioned by two caregivers. When discussing her child's university course load one caregiver stated, "...He does the normal amount of courses that he can, maybe two a term.....he has failed a few courses and had to do a couple of courses [over]."

Four caregivers discussed their child's experiences in the workplace. One caregiver revealed that her child works at a funeral home, stating, "...he washes the cars and general things around the office and yard work...They have tried to accommodate him, they know his limitations... they understand...They specifically looked for somebody with autism who is functional." Another caregiver discussed her child's former employment at a coffee shop, "...[she would] clean windows, tables... she lasted a long time there."

Theme C: Struggling to Stay Hopeful

Participants considered their present challenges and their concerns about the future. They reported coping with their children's anger and emotional outbursts as the most challenging experience. One participant said, "He has had a lot of outbursts, a lot of problems controlling his anger...When he does have a sudden outburst, he has physically attacked both myself and our roommate...[He] screams at us, mostly me." Another caregiver revealed that her child's "behavior got worse and got more aggressive, and at one point he got in a big fight...with the cook and he hit the cook in the back with a 2 by 4. Again he was put in the hospital, but [was] let go in 72 hours." Participants described how they had to constantly monitor their children. Additionally, parents had to cope with public reaction. As one participant expressed, "...you are looked at

strangely if your child is 'misbehaving' or acting not normal...my family and my friends [were] thinking that it was just me, I was being a bad parent...instead of offering assistance and help to him, just threw me in parenting courses..." As another participant explained, "...we couldn't do a lot of things..."

Other difficult experiences centred on financial strains, especially when the funding many participants received was never enough to be able to support all of their child's needs. One participant stated that it was "pretty frustrating" when the government funding they received was not enough for their child to be able to live on their own. Another caregiver reported that they did not have the funds for transportation, saying, "I can't afford to take a taxi. I can't afford to take a bus." Due to lack of funds, three caregivers reported having to pay out of pocket for services that their child needed.

When considering their children's futures, one overwhelming fear took precedence in the minds of caregivers: what would happen to their child when they were no longer able to care for them. This fear was expressed by eight caregivers. One caregiver stated, "I am not going to be there forever. This hangs over me every day... For sure, you can't imagine one day you are not going to be there to do things and take care of her. You cannot imagine that." Another caregiver revealed the many questions that were arising in her mind: "What is going to happen? Where is she going to be? What if something happens to me?" For the most part, parents hoped that their children would be in a supportive group home. As one parent stated, "It would be nice to know exactly in four to five years where they are going to be..." Parents hoped that their children would be well cared for once they were unable to do so. As one caregiver expressed, "I want to make sure there is something there for my son if I'm not around here anymore. I want to make sure my son is cared for in the best way that he is entitled to."

Theme D: Coping with Stigma.

The participants' discussions about their thoughts and feelings surrounding their children's diagnosis and how others reacted to their children highlighted the impact of social stigma. Partici-

pants said that the most frequent test administered to their children during the diagnosis process was a psychological evaluation. When discussing her frustrations with the testing her son received, one caregiver stated, "It took three psychological assessments to get him diagnosed with autism."

Participants discussed their perceptions of raising a child with a dual diagnosis and how it influenced their perception of individuals with disabilities. Three caregivers revealed that caring for their child became easier as their child became older. As one participant stated, "He has come a long way...He's learning to handle things a little better and I'm proud." Participants viewed caring for their child as a long-term commitment. One caregiver revealed, "We started out when he was really young. You say, 'Okay, this will pass, and things will become normal.' Well, they never do; then you think, 'Are we going to do this our entire lives?'" The experience of caring for a child with a dual diagnosis also revealed the importance of self-advocacy to ensure their child would receive the necessary supports. As one participant stated, "My strength has been that I have pretty much helped myself, and any help that I have gotten is because I have pushed for it or fought for it." Another caregiver said, "I have to step up to the plate, and I have to fight not only for my son who has autism; I'm fighting for every other child that's been diagnosed..."

Participants also discussed the need for educating the public regarding disabilities, specifically mentioning the need for further education for teachers and caregivers. One caregiver discussed how parents of children with disabilities are in an excellent position to teach others. "I always say the best person to teach a child is the parent," said the survey participant. "...we're the ones that spend hours on end teaching our children ABA [Applied Behaviour Analysis] once we're taught. Who else could do that better than us, the parents?"

Participants also discussed their hopes that the research they were participating in would educate others and assist in improving experiences for caregivers. As one caregiver said, "I really hope the results of this will bring a positive result for people like us."

Limitations

The limitations include relying on respondent pool of southwestern Ontario residents. Also, using an interview guide placed the research at risk for being limited by defined questions prepared in advance of the research. Moreover, this study did not address the health of aging female caregivers although research indicates it is strongly correlated with quality of life, suggesting caregiver personal health affects their perceptions of their ability to care for their child and others (Chou et al., 2011). Finally, in the analysis, the themes identified in this study do not represent all of the categories of coded data created; choices had to be made about what would be reported.

Discussion

Caregivers of adult children with a DD face a variety of challenges that affect their abilities to cope while raising their children. Primary concerns include obtaining services and resources, lack of funding for programs and services, and planning for their child's future care. Caregivers also mentioned the stigma that their children have faced within educational institutions and when interacting with the general public. Alternately, caregivers mentioned positive factors that they experienced while raising a child with a DD. These included experiences in which teachers and support workers went above and beyond to assist their children, and relationships that they formed with other parents of children with disabilities. The various organizations and medical personnel who provided support and advice over the years were also mentioned positively by caregivers. In addition, caregivers appreciated the fact that the general public has become more knowledgeable and accepting of individuals with disabilities in recent years, although they also acknowledged that there is still much work to be done.

The caregiver interviews support many of the findings observed in recent literature. As previously mentioned by Saldaña et al. (2009), many of the caregivers experienced a lack of social and community supports while caring for their children. Caregivers also noted a lack of peer relationships for the children and that their closest friendship was often with their support workers, a finding

also documented by Lunsky et al. (2014). Another challenge mentioned by caregivers and supported in the literature by Haley & Perkins (2004) was financial stress. Many caregivers expressed frustration at the lack of funds they received for programs and services to assist their children. Additionally, caregivers mentioned the stress of planning for their child's future care and the wait lists associated with group homes.

Caregivers also discussed the many coping methods they used, which were supported by findings in the literature. One method of coping utilized by caregivers and mentioned by Ha, Greenberg, and Seltzer (2011) was support and positive interactions among household members. The caregivers interviewed reported less stress when their family members supported each other and worked as a team. Research has also demonstrated that caregivers' coping skills can increase and improve through the time and experiences gained caring for their children (Grant & Whittell, 2000; Heiman, 2002). Many caregivers said that caregiving became easier as their child grew and they became more knowledgeable of supports and resources. This matched Heiman's (2002) assertion that support from medical professionals, social workers, support groups and others can increase caregiver resilience. Our study also found this, as many caregivers praised the support that they received from medical professionals, support workers, and support groups.

Our study results suggest a number of recommendations for assisting aging caregivers of children with a DD. We strongly suggested that caregivers research group homes in their area while their child is young, and place their child on a wait list as soon as possible. As mentioned during the interviews, the primary fear for caregivers is what will happen to their child when they are no longer able to care for them. Many caregivers also voiced the hope that their children will eventually go into in a group home environment where they will receive the support they need but are still able to maintain some independence.

The long process of getting a child placed on a wait list for a group home and waiting for a room to become available was a concern for many parents. One caregiver said, "I'm trying to get him

into a group home... last time I talked to [the] lady in charge of that she said they are trying to find some place that could accommodate...but right now everything's full...He is on the waiting list."

Caregivers also mentioned the challenges of supervising the workers who assist their children, and some discussed various unethical behaviours of previous workers. One caregiver expressed her disappointment by stating, "The worker had been telling him that he was going to quit and take another job if I didn't pay him more. So [my son] would come back and demand that I pay the worker more, which is really unethical for the worker to do ... At that point I knew I had to fire him..." It is assumed that the difficulty in obtaining funding for their children and the length of wait-lists for programs and services may result in caregivers hiring less-than-reputable agencies or individuals to work with their children. The authors recommend that caregivers be made aware of reputable support work agencies as well as techniques to supervise their child's workers. These workshops should include information sharing by caregivers who have had extensive experience hiring and collaborating with support workers for their adult children. The caregivers who help to facilitate the workshops may also be able to offer advice on obtaining additional government funding for support workers and other programs and resources. For example, many caregivers expressed interest during the interviews in assisting other caregivers in similar situations, with one caregiver stating, "Whenever I'm here, I go to speak to families and groups."

In conclusion, the interviews with caregivers demonstrated that various supports were essential while raising their children. Having the support of others--whether immediate family members, other parents, support workers, teachers, or medical personnel--has a positive impact on caregivers' ability to cope while raising their children. This support also had a positive influence on their children and assisted them in developing and increasing their abilities. As a result, some children have been able to participate in such activities as attending university and seeking employment. Many of the moments when caregivers experienced challenges or

difficulty coping were directly related to a lack of support and funding.

As a result, it is encouraged that caregivers of adult children with a DD become guides for the next generation of caregivers, sharing advice and resources that they found to be helpful. This would increase the coping abilities of caregivers and improve the lives of the next generation of children who receive a DD. However, it must be noted that the ability of caregivers to assist each other does not negate the need for professional supports to augment such informal networks. Professionals and caregivers must work together in order to reduce stigma and enhance supports. In this vein, our study underscores the following recommendations from the literature:

- Longitudinal research should be conducted regarding the relationships between caregivers, siblings, and the individuals with a disability diagnosis to examine their perceptions and coping skills (Heiman, 2002).
- Service providers should increase their knowledge of the various challenges caregivers face as well as their coping techniques (Jones & Passey, 2004).
- Additional research should examine the correlation between stressors and crisis severity, and if certain coping techniques can moderate the effects of the stress (Weiss & Lunskey, 2011).
- The medical community should increase its focus on the health of aging caregivers and view them as additional patients (Cjpi. Fu, Lin, & Lee, 2011).
- When providing interventions to individuals with a DD, it is important to separate the effects and impact of behavior issues from mental health issues in order to determine the most effective interventions (Esbensen, 2011).
- The internet can be increasingly useful as a support method for aging caregivers and should be highlighted and further developed. Caregivers can increase their knowledge as well as participate in supportive online conversations with other caregivers (Perkins & LaMartin, 2012).

References

- Altiere, M. J., & von Kluge, S. (2009). Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies, 18*(1), 83-92.
- ATLAS.ti Scientific Software Development (2002-2014). *ATLAS.ti 7*. Retrieved from <http://www.atlasti.com/>
- Canada Health Act (1984). Government of Canada. 1984-04-01. Retrieved from <http://www.parl.gc.ca/content/lop/researchpublications/944-e.htm>
- Cappe, E., Wolff, M., Bobet, R., & Adrien, J. L. (2011). Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. *Quality of Life Research, 20*(8), 1279-1294. doi: 10.1007/s11136-011-9861-3.
- Chou, Y. C., Pu, C. Y., Lee, Y. C., Lin, L. C., & Kröger, T. (2009). Effect of perceived stigmatization on the quality of life among aging female family carers: A comparison of carers of adults with intellectual disability and carers of adults with mental illness. *Journal of Intellectual Disability Research, 53*(7), 654-664. doi:10.1111/j.1365-2788.2009.01173.x.
- Chou, Y. C., Fu, L. Y., Lin, L. C., & Lee, Y. C. (2011). Predictors of subjective and objective caregiving burden in older female caregivers of adults with intellectual disabilities. *International Psychogeriatrics, 23*(4), 562-572. doi:10.1017/S1041610210001225.
- Chou, Y. C., Lee, Y. C., Lin, L. C., Kroger, T., & Chang, A. N. (2009). Older and younger family caregivers of adults with intellectual disability: Factors associated with future plans. *Intellectual and Developmental Disabilities, 47*(4), 282-294.
- Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors. *British Journal of Psychiatry, 190*, 27-35. doi:10.1192/bjp.bp106.022483.
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Engel, R. J., & Schutt, R. K. (2013). *The practice of research in social work* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Esbensen, A. J. (2011). Families of individuals with intellectual disability and comorbid mental health problems. *Journal of Mental Health Research in Intellectual Disabilities, 4*(3), 140-157. doi: 10.1080/1931586.2011.597018.
- Foulks, E. F. (2000). Advocating for persons who are mentally ill: A history of mutual empowerment of patients and profession. *Administration and Policy in Mental Health, 27*(5), 353-367.
- Gerstein, E. D., Crnic, K. A., Blacher, J., & Bak, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research, 52*(12), 981-997. doi:10.1111/j.1365-2788.2009.01220.x.
- Gough, H., & Morris, S. (2012) Dual diagnosis public policy in a federal system: The Canadian experience. *Journal of Policy and Practice in Intellectual Disabilities, 9*(3), 166-174. doi: 10.1111/j.1741-1130.2012.00347.x.
- Grant, G., & Whittell, B. (2000). Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the life span. *Journal of Applied Research in Intellectual Disabilities, 13*(4), 256-275.
- Greenstone, J. D. (1979). Dorothea Dix and Jane Addams: From transcendentalism to pragmatism in American social reform. *Social Service Review, 53*(4), 527-559.
- Grinnell, R. M., Jr., & Unrau, Y. A. (2014). Social work research and evaluation: Foundations of evidence-based practice (10th ed.). New York: Oxford University Press.
- Hollins, S., Attard, M. T., von Fraunhofer, N., McGuigan, S., & Sedgwick, P. (1998). Mortality in people with learning disability: Risks, causes and death certification findings in London. *Developmental Medicine and Child Neurology, 40*(1), 50-56. doi: 10.1111/j.1469-8749.1998.tb15356.x.
- Holosko, M. J. (2006). *Primer for critiquing social research: A student guide*. Toronto: Thomson.
- Haley, W. E., & Perkins, E. A. (2004). Current

- status and future directions in family caregiving and aging people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1(1), 24-30. doi: 10.1111/j.1741-1130.2004.04004.x.
- Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities*, 14(2), 159-171. Retrieved from http://resolver.scholarsportal.info.ezproxy.uwindsor.ca/resolve/1056263x/v14i0002/159_pocwdrcafe.
- Heiman, T., & Berger, O. (2008). Parents of children with Asperger syndrome or with learning disabilities: Family environment and social support. *Research in Developmental Disabilities*, 29(4), 289-300. doi:10.1016/j.ridd.2007.05.005.
- Johnston, C. (2000). The asylum's alienist: Dr Joseph Workman, the father of Canadian psychiatry, fought to change attitudes about the mentally ill during the mid-1800s. *Medical Post*, 36(22), 45.
- Jones, J., & Passey, J. (2004). Family adaptation, coping and resources: Parents of children with developmental disabilities and behaviour problems. *Journal on Developmental Disabilities*, 11(1), 31-46.
- King, G. et al. (2003). Turning points and protective processes in the lives of people with chronic disabilities. *Qualitative Health Research*, 13(2), 184-206. doi: 10.1177/1049732302239598.
- Kring, S. R., Greenberg, J. S., & Seltze, M. M. (2008). Adolescents and adults with autism with and without co-morbid psychiatric disorders: Differences in maternal well-being. *Journal of Mental Health Research in Intellectual Disabilities*, 1(2), 53-74. doi:10.1080/19315860801988228.
- Lloyd, T. J., & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 53(12), 957-968. doi:10.1111/j.1365-2788.2009.01206.x.
- Lunsky, Y. (2003). Depressive symptoms in intellectual disability: does gender play a role? *Journal of Intellectual Disability Research*, 47(6), 417-427. doi:10.1046/j.1365-2788.2003.00516.x.
- Lunsky, Y., Tint, A., Robinson, S., Gordeyko, M., & Ouellette-Kuntz, H. (2014). System-wide information about family carers of adults with intellectual/developmental disabilities—A scoping review of the literature. *Journal of Policy and Practice in Intellectual Disabilities*, 11(1), 8-18. doi: 10.1111/jppi.12068.
- Miettinen, S. (2012). Family care of adults with intellectual disabilities: Analysis of Finnish policies and practices. *Journal of Policy and Practice in Intellectual Disabilities*, 9(1), 1-9.
- Minnes, P., & Woodford, L. (2004). Well-being in aging parents caring for an adult with a developmental disability. *Journal on Developmental Disabilities*, 11(1), 47-66.
- National Association for the Dually Diagnosed. (2012). Information on Dual Diagnosis. Retrieved from <http://thenadd.org/resources/information-on-dual-diagnosis/>.
- National Association for the Dually Diagnosed, Ontario Chapter (2004). *Response to the government Transformation Agenda for Developmental Services: Meeting the health and mental health needs of individuals with developmental disabilities*. Sudbury, ON. Retrieved from: www.naddontario.net/pdf/FinalResponseToTransformationAgenda.pdf.
- Neufeldt, A. H. (2003). Growth and evolution of disability advocacy in Canada. In D. Stienstra & Wight-Felske (Eds.), *Making equality: History of advocacy and persons with disabilities in Canada* (pp. 11-32). Concord, Canada: Captus Press Inc.
- Olsson, M. B., & Hwang, C. P. (2008). Socioeconomic and psychological variables as risk and protective factors for parental well-being in families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 52(12), 1102-1113. doi:10.1111/j.1365-2788.2008.01081.x.
- Ontario Human Rights Commission (2012). Disability and human rights. Retrieved from <http://www.ohrc.on.ca/en/disability-and-human-rights>.
- Perkins, E., & LaMartin, K. (2012). The internet as social support for older carers of adults with intellectual disabilities. *Journal of Policy and*

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- Practice in Intellectual Disabilities*, 9(1),53-62.
- Radford, J. & Park, D. (2003). Chapter 1: Historical overview of developmental disabilities in Ontario. *Developmental disabilities in Ontario*. I. Brown and M Percy (Eds). Toronto, Ontario: Ontario Association on Developmental Disabilities.
- Saldaña, D., Álvarez, R. M., Lobaton, S., Lopez, A. M., Moreno, M., & Rojano, M. (2009). Objective and subjective quality of life in adults with autism spectrum disorders in southern Spain. *Autism*, 13(3), 303-316. Retrieved from <http://journals2.scholarsportal.info/tmp/16339137323427923065.pdf>.
- Scientific Software Development (2012). AT-LAS.ti7. GmbH, Berlin. Retrieved from http://www.atlasti.com/uploads/media/WhatsNew_a7_01.pdf.
- Shu, B. C. (2009). Quality of life of family caregivers of children with autism: The mother's perspective. *Autism*, 13(1), 81-91. doi:10.1177/1362361307098517.
- Spratt, E. G., Saylor, C. F., & Macias, M. M. (2007). Assessing parenting stress in multiple samples of children with special needs (CSN). *Families, Systems, & Health*, 25(4), 435-449. Retrieved from http://resolver.scholarsportal.info.ezproxy.uwindsor.ca/resolve/10917527/v25i0004/435_apsimsocwsn.
- Statistics Canada (2006). Type of disability. Canadians in Context—People with Disabilities (2006). *Persons with disabilities, by age group and sex (2006)*. Retrieved from: http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=40#M_4.
- Unwin, G., & Deb, S. (2011). Family caregiver uplift and burden: Associations with aggressive behavior in adults with intellectual disability. *Journal of Mental Health Research in Intellectual Disabilities*, 4(3), 186-205. doi: 10.1080/19315864.2011.600511.
- Ward, R. L., Nichols, A. D., & Freedman, R. I. (2010). Uncovering health care inequalities among adults with intellectual and developmental disabilities. *Health and Social Work*, 35 (4), 280-290.
- Weiss, J. (2012). Mental health care for Canadians with developmental disabilities. *Canadian Psychology*, 53(1), 67-69. doi: 10.1037/a0026127.