Care Experiences of Adults With a Dual Diagnosis and Their Family Caregivers

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Abstract

Individuals diagnosed with developmental disability and mental illness (a “dual diagnosis”) contend with multiple challenges and system-related barriers. Using an interpretive description approach, separate qualitative interviews were conducted with adults with a dual diagnosis (n = 7) and their caregiving parents (n = 8) to examine care-related experiences. Results indicate that individuals with a dual diagnosis and their families experience misunderstanding and stigma. Families provide informal complex care amid insufficient and uncoordinated services but are often excluded from formal care planning. A lack of available funding and services further impedes care. While negative care experiences are reported as prevalent, participants also describe instances of beneficial care. Overall, findings indicate a lack of sufficiently targeted resources, leaving families to absorb system-related care gaps. Recommendations include person- and family-centered care, navigation support, and capacity building. Prevention and emergency and crisis care services, along with housing, vocation, and other supports, are needed. Practice and research development regarding life span needs are recommended.

Keywords

disability, developmental; health care; lived experience; mental health and illness

Introduction

Individuals diagnosed with both a developmental disability and a mental health condition (termed a “dual diagnosis” within this article) contend with multiple challenges and systems-related barriers (Davis, Barnhill, & Saeed, 2008; James, 2012; Venville, Sawyer, Long, Edwards, & Hair, 2015), rendering them among the most vulnerable in communities (Bongiorno, 1996; Davis et al., 2008). Developmental disabilities are defined as conditions that result in significant limitations in adaptive skills that emerge in childhood (Government of Alberta, 2000), including disabilities that are genetic in origin; caused by illness or prenatal or childhood injury (e.g., fetal alcohol spectrum disorder); and/or of unknown origin (e.g., autism spectrum disorder) (Centre for Addiction and Mental Health, 2012). Developmental disabilities often, but not always, include intellectual or cognitive deficit. Lusnky et al. (2013) note that various jurisdictions use different terminology to describe the same or similar disabilities; for example, developmental disability and intellectual disability have been used synonymously (Sullivan et al., 2011).

Developmental disability populations experience high prevalence rates of coexisting mental health challenges (Einfeld, Ellis, & Emerson, 2011). Between 30% and 57% of people with a developmental disability are estimated to experience a concurrent mental health challenge in industrialized countries including Canada (Biefska, Ouellette-Kuntz, & Hunter, 2012), Australia (Trollor, 2014), and the United Kingdom (Bhaumik, Tyer, McGrathor, & Gnhhadaran, 2008; Cooper, Smiley, Morrison, Williamson, & Allan, 2007). Emerging evidence suggests that, compared with the nondisabled population, people with developmental disabilities are at greater risk for challenges related to difficulties accessing health care and insufficient emotional support (Azimi, Modi, Hurlbut, & Lusnky, 2016; Havercamp & Scott, 2015; Trollor, 2014). Furthermore, people with developmental disabilities are at heightened risk for poorer overall health, subjection to abuse, stigma, and reduced quality of life (Bowman, Scotti, & Morris, 2010; Havercamp & Scott, 2015; Jones, Gallus, Viering, & Oseland, 2015; Moss, Bouras, & Holt, 2000; Sullivan et al., 2011).

The 2005 expenditure for mental health in the United States was approximately US$113 billion in comparison
with approximately US$32 billion in 1986. Only 26.7% of the 2005 expenditure was spent on hospital care, as opposed to 42.8% in 1986 (Substance Abuse and Mental Health Services Administration, 2010). Accordingly, it appears that proportionately less hospital-based care has been offered over time. Along with increased prioritization of care in the community, the most severely ill (including those with a dual diagnosis) may be at heightened risk of incarceration (National Research Council, 2014). In part, increased overall prison sentence prevalence is thought by some to be potentially associated with deinstitutionalization and an overall lack of treatment in the community (National Research Council, 2014). This appears to signify a lack of careful planning, coordination, and implementation of resources to proactively and sufficiently address the needs of this vulnerable population.

High-income countries such as the United States, Canada, and Australia rely predominantly on mainstream or generalist service approaches, including mental health services for people with developmental disabilities. Generalist services by definition lack specialist expertise relative to dual diagnosis populations (Salvador-Carulla et al., 2015). In a review of Canadian federal and provincial/territorial statutes and regulations related to developmental disabilities and mental health/illness, Gough and Morris (2012) report that no provincial or territorial legislation or regulation “explicitly recognize . . . dual diagnosis” (p. 168). Generic disability services may be perceived as providing equal service across disabilities; however, concerns remain regarding the ability of such approaches to respond to the heterogeneity and potentially expansive needs of individuals with a dual diagnosis (Gough & Morris, 2012). While firsthand research from the perspective of these individuals themselves and their family members is limited, a recent review of available studies indicates that mainstream psychiatric care is often experienced as disempowering and generally negative (Venville et al., 2015). Mental health facilities that offer specialized treatment to people with intellectual disabilities are characterized by service users as considerably more tailored to their needs, but many service users continue to describe “negative” and belittling treatment from facility staff members (Venville et al., 2015, p. 199).

Collaborative approaches between sectors such as health and social services have begun to emerge (Raghavan & Patel, 2008). For example, the United Kingdom offers individuals with a dual diagnosis access to mainstream services, specialist services, or a combination of both including mental health services (Rose, Kent, & Rose, 2012). In a study examining a specialized hospital-based psychiatric unit for persons with learning disabilities in Hong Kong, an integrated multidisciplinary inpatient team with community outreach capacity is reported to yield favorable outcomes and satisfaction among care recipients and providers (Kwok, 2001). This model enables more accurate diagnoses given the team’s expertise related to atypical presentation and proficiency in working with a learning disabled population. Moreover, therapeutic mental health interventions can be modified to accommodate learning disabilities.

In Ontario, Canada, there has been a shift from an institutional model of care to community-based services and supports (Lunsky et al., 2013). The Government of Ontario has focused on transforming services for individuals with developmental disabilities that better support the agency of the individual to live in the community and promote full social inclusion (Lunsky et al., 2013). Moreover, international clinicians and researchers have created “consensus guidelines for primary health care of adults with developmental disabilities” (Sullivan et al., 2011) that inform care for adults with a dual diagnosis. These guidelines offer recommendations for interdisciplinary care, including patient and family/caregiver input in treatment.

Families living with an individual with a dual diagnosis require support and services. With the ongoing transition from deinstitutionalization and an increasing emphasis on community integration and inclusion of people with developmental disabilities, a greater proportion of families are caring for their adult children with a dual diagnosis (Lunsky et al., 2013; Weeks, Nilsson, Bryanton, & Kozma, 2009). Research indicates that stress levels within these families are considerable, compared with families in which an individual has a developmental disability but no coexisting mental health diagnosis. This is particularly true if the individual with a dual diagnosis exhibits problematic behaviors (Maes, Broekman, Dosen, & Nauts, 2003; McIntyre, Blacher, & Baker, 2002; Weiss & Lunsky, 2010).

While increased attention has been paid to the care needs of individuals with complex conditions, relatively little is known about care navigation and experiences of individuals with a dual diagnosis and their families (James, 2012; Venville et al., 2015). To address this gap, this study aimed to elicit such experiences among individuals with a dual diagnosis and their caregiving parents. It is theoretically grounded on the International Classification of Functioning, Disability and Health (ICF) framework (World Health Organization [WHO], 2002). The ICF framework identifies and classifies health and health-related domains in bodily (in this case, development and mental health function) as well as environmental factors. Focus and concern are amplified relative to causal elements that result in impaired health outcomes for individuals with disability, including elements that impede their active and generative participation in the community. The ICF framework thus recognizes functioning relative to health/mental health and disability as well as environmental factors (e.g., care delivery) as facilitative and/or impeding elements (WHO, 2002). Relative to the aims of this study, this framework assists in amplifying elements to consider in terms of individual health, well-being, and engagement in community life. Research questions addressed in this article, as part of a larger study, are as follows:
Research Question 1: What are the experiences and perceived care needs of adults with a dual diagnosis and their family caregivers?

Research Question 2: From the perspectives of adults with a dual diagnosis and their family caregivers, what is required to facilitate effective care?

Method

A qualitative design was implemented, based on an interpretive description approach. Interpretive description is an established method of qualitative inquiry that informs practice through data generation and analysis processes that remain intentionally close to aims of improving clinical practice and program design (Thorne, 2016). Interpretive description provides “smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding” (Thorne, Reimer, Kirkham, & O’Flynn-Magee, 2004, p. 5). Given the pressing need for guidance for clinical practice and program development with this population, this approach emerged as ideal for the study. Separate interviews were conducted with adults with a dual diagnosis and their caregiving parent, with interview questions eliciting open-ended responses. Interview questions entailed items inviting firsthand experience such as “Describe your (or your adult daughter/son’s) experiences of care relative to your (or their) condition?”

For participants with a dual diagnosis, inclusion criteria consisted of (a) a confirmed concurrent developmental disability and mental health condition based on clinician corroboration; (b) complexity of care needs as demonstrated by at least one related acute (in hospital) admission within 2 years of study enrollment, as well as ongoing community care; and (c) age greater than 17 years. Parents were in frequent contact as defined by a minimum of weekly contact with, and/or direct care for, their family member with a dual diagnosis. This care included medication administration, supports at home (e.g., meal preparation), advocacy, navigation of services, application for and management/comanagement of funding, and/or transportation provision.

A dyadic/family approach to data collection, consisting of data elicited from the individual with a dual diagnosis and their parent, was anticipated to thicken experiential understanding about individual and family experience. However, the potential for different perspectives was also recognized. An advantage of this approach of engaging the individual with a dual diagnosis and their family caregiver was the potential for broader yet also comparative data about the experiences of families (and family members therein) confronted with a dual diagnosis and resulting care needs.

Potential participants were referred from a regional health care provider, who confirmed eligibility and initially informed families about the study. If the potential participant was interested in further information about the study, service providers obtained his or her consent to release contact information to the research team. The potential participant was then contacted by a research team member who explained the purpose and details of the study, and inquired about interest in continuing engagement in the study. Potential participants were informed that their participation was entirely optional, and written consent was obtained from all participants. The process of seeking consent, including consent form content, was similar for both groups (parents and individuals with a dual diagnosis); however, wording and approach were modified related to potential issues for individuals with cognitive issues. As an example, simpler language related to processes of the study was available in the aim of offering greater ease of understanding for potential participants for whom this modification would be helpful. In recruitment, there were no instances in which cognitive and communication issues were viewed to preclude potential participants’ ability to consider or convey their wishes relative to study participation. Of importance, we attempted to emphasize that participation was optional to ensure no coercion or perceived influence to participate. Furthermore, institutional ethics review board approval was received prior to study commencement. In the participant dyads, no information was shared about an interviewee (or interview) with their counterpart interviewee, that is, other family member also being interviewed. All identifying data were removed from transcripts prior to data analysis.

Participants were engaged in semistructured interviews which lasted an average of 1 hour and were conducted by a graduate student who was extensively trained and supervised by the principal investigator. The interviews were digitally recorded, transcribed verbatim, and analyzed using NVivo 10 data analysis and management software (QSR International, 2012). Data analysis consisted of line-by-line coding, categorization and interconnection of emergent codes within and across transcripts, and review of codes for emergent patterns and distillation into themes. Diverse positionalities (individuals with a dual diagnosis vs. parents) were examined by initial review of data within groups (e.g., individuals with a dual diagnosis and then parents) and subsequently across groups. Rigor (trustworthiness and authenticity) of qualitative findings was demonstrated through interrater review completed between the coder and the principal investigator, peer debriefing after initial data analysis was completed, data saturation and theme corroboration via triangulation.

Results

The Sample

Participants with a dual diagnosis (n = 7) included adults with a self-reported developmental disability and a mental illness. Mental illnesses included attention deficit disorder, bipolar
disorder, obsessive compulsive disorder, schizophrenia, anxiety disorder, and depression. Developmental disabilities consisted of autism spectrum disorder, fetal alcohol spectrum disorder, intellectual disability, and global developmental delay, with comorbid intellectual impairment in some cases that ranged across mild, moderate, and severe levels. For several families, the individual’s mental health issue was perceived as the most pressing concern requiring monitoring and care, although multiple challenges sometimes rendered it difficult to decipher whether the primary issue reflected mental illness or developmental disability. In all cases, the condition of participants with a dual diagnosis resulted in at least one hospital admission related to the dual diagnosis within the previous 2 years and continuing care needs (eligibility criteria for participation). Caregiving parents (n = 8; in one family, both parents were conjointly interviewed) resided in the same region as participants with a dual diagnosis, and seven of eight parents were married, with just more than half of the parents being employed. All participants resided in urban or rural communities in central and northern Alberta, Canada, and were racially diverse. Table 1 offers additional demographic information for participants with a dual diagnosis.

| Sex | Location | Age | Identified Diagnoses                                                                 | Highest Level of Education | Employment Status |
|-----|----------|-----|-------------------------------------------------------------------------------------|-----------------------------|-------------------|
| F   | Urban    | 19  | Intellectual disability, apraxia, autism spectrum disorder, mental health issues (specific mental health diagnosis not disclosed) | Some high school            | Unemployed        |
| F   | Urban    | 20  | Intellectual disability, posttraumatic stress disorder, reactive attachment disorder, depression, oppositional defiant disorder, borderline personality disorder, schizoaffective disorder, bipolar disorder | Some high school            | Unemployed        |
| F   | Urban    | 32  | Fetal alcohol spectrum disorder, obsessive compulsive disorder, seizures, schizophrenia | High school completion      | Unemployed        |
| M   | Urban    | 25  | Global developmental delay, mental health issues (specific mental health diagnosis not disclosed) | High school completion      | Unemployed        |
| F   | Rural    | 18  | Fetal alcohol spectrum disorder, attention deficit disorder, depression              | High school completion      | Employed          |
| M   | Rural    | 24  | Autism spectrum disorder (Asperger’s syndrome), paranoia                               | Not disclosed               | Unemployed        |
| M   | Urban    | 21  | Autism spectrum disorder, obsessive compulsive disorder                               | Some high school            | Not disclosed      |

An individual with a dual diagnosis commented on broader stigmatizing discourses which left him feeling dismissed and marginalized:

“I’m pretty much still stigmatized in our society. People look at people who have mental illness completely different. I don’t tell people that I have bipolar, and most of them don’t know and don’t need to know.

Beyond feeling misunderstood and overlooked, participants with a dual diagnosis described a range of challenges associated with their care-related needs. Challenges associated with a dual diagnosis resulted in the need for care, which was often at least partially provided by informal carers such as parents or other family members. This requisite for informal care was viewed as largely reflective of insufficient and uncoordinated professional services, along with a lack of ancillary resources such as housing and transportation. The following themes emerged from analysis of the data: (a) the need for informal complex care amid gaps in an uncoordinated system, (b) difficulties exacerbated by insufficient funding and housing, and (c) parental support as depended upon yet sometimes dismissed. The corollary to these largely negative themes were instances of (d) supportive care for people with a dual diagnosis. Each of these emergent themes is addressed below.

The Need for Informal Complex Care Amid Gaps in an Uncoordinated System

Participants identified challenges that reflect difficult states and behaviors in their adult child with a dual diagnosis for which professional and paraprofessional help was sought including institutional and community-based supports. Extreme anxiety, depression, violence, aggression to self or others, suicidal ideation and/or attempts, and substance abuse were described. As an example, a parent shared, “He [her son] was sort of out of control [such] that he . . . was ending up hitting us—me and my husband—and we just...
had many, many admissions into [a health care facility], and adult child’s diagnostic trajectory, a parent stated, “He’s . . . assessments yet diagnostic confusion. Referring to her continual struggle even during hospitalizations: “Well, he’s well loved, and his sisters help me out as well. They will have him in their homes for short visits. They always back me up.”

Another parent shared that there would be great difficulty for individuals with autism spectrum disorder if they did not have family support: “I don’t know what would have happened to [him] if he didn’t have a strong family.” Parents described and demonstrated a long-standing commitment to their adult child, along with a deeply ingrained sense of obligation which in turn compelled them to continue to provide care. A parent illustrated this commitment stating, “I love my daughter and I would do anything for her, and I want to make sure that I do my job.” Another added, “He’ll always be our son and I’ll always be involved.”

Caregiving parents identified a range of strategies that both ensured ongoing care and helped them personally cope with what often was described as unending care demands. Such strategies included scheduling and organization, developing hobbies which offered enjoyment or distraction, participating in education/support programs, building knowledge, gaining information about navigating the system, staying determined, and choosing to not focus on negative thoughts. Beyond providing daily care, most parents sought and/or coordinated resources to address their adult child’s needs. One mother described personal exhaustion, yet she perceived herself to be unable to cease advocating for her son: “I keep getting forms that if [my child] doesn’t get all the disability payments could be canceled, with a minimum IQ threshold. A parent of a young man who had obtained funding, nonetheless, identified difficulties accessing and maintaining government disability transfer payments for their adult child exceeding a dual diagnosis, families were conveyed as devoted to their adult, along with a deeply ingrained sense of obligation which in turn compelled them to continue to provide care. A parent illustrated this commitment stating, “I love my daughter and I would do anything for her, and I want to make sure that I do my job.” Another added, “He’ll always be our son and I’ll always be involved.”

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Family care provision, reflective of this lack of community supports, reportedly imposed intense challenges and impacts on caregivers such as depression, anxiety, health challenges, decreased engagement in the community, and fewer social relationships outside the family. As illustrated above, parents lived in what was described as a tenuous state of substantial responsibility for care with no or limited authority in accessing supports for managing that care.

**Difficulties Exacerbated by Insufficient Funding and Housing**

Individuals with a dual diagnosis and their parents reported substantial difficulties associated with meeting basic living expenses and core needs. A parent shared that in schools “there’s only so much assessment dollars, so we had to pay . . . out of our own pocket . . . ” Several reported being unable to access disability supports due to their adult child exceeding a minimum IQ threshold. A parent of a young man who had obtained funding, nonetheless, identified difficulties accessing and maintaining government disability transfer payments for her son: “I keep getting forms that if [my child] doesn’t get all this figured out within the next 30 days, his [disability benefit payment] will be [canceled]—that it will have to be voided.”

A participant noted that if dually diagnosed participants remained hospitalized beyond a predetermined length of time, their disability payments could be canceled, with
eligibility and reinstatement processes reportedly mired in bureaucratic procedures and potential time delay. A parent stated,

You would not believe what it’s like to try and get an adult back on [financial support] again once they’ve been sort of lost to that system; it’s almost impossible. And it’s almost impossible to get them another [behavioral support or family care respite] contract.

Families lacked clarity about reasons for policy restrictions and changes, with some reporting that their financial support worker had frequently changed. If an individual was repeatedly hospitalized, new costs were reportedly incurred by families upon discharge: “We often have to buy him new furniture, new clothing; he’s got nothing and is moving into a home that may or may not have a bed for him.”

Participants reported difficulty retaining residential options outside the family home, especially if dually diagnosed individuals exhibited complex behavior such as a history of aggression or self-harm. Existing facilities were described as insufficiently resourced to meet complex needs for such placement, often resulting in eviction and lengthy waiting lists (or being “blacklisted” which restricted future placement). One mother reflected on her struggle to seek a housing placement: “Someone like [my child] doesn’t qualify for the mental health beds. There’s a place in [city] that is low subsidy housing for people with mental health issues, and even though [my child] is dually diagnosed, he didn’t qualify.”

Community-based housing as opposed to institutional housing was preferred by participants; however, the needs of individuals with complex dual diagnoses sometimes exceeded the staff’s capacity in residential facilities such as group homes. As a result, placement in hospital, living at home with family, moving to unsafe independent living environments, or homelessness were commonly described outcomes. Rural dwellers who had moved to urban centers to access supported housing described mixed outcomes in trading geographic proximity to family and other informal supports for a more targeted residential placement and/or services only available in the urban center.

**Parental Support Depended Upon yet Sometimes Dismissed**

Parents recognized family-centered care as an approach in mental health services that tended to be more readily espoused by the health system until the youth reached 18 years of age, at which point they felt that this approach largely ended. One such example involved key information about a severely affected dually diagnosed individual’s care that was not shared with a parent by health care providers. Another parent reported that despite the fact that ongoing family involvement in care was critical for her daughter’s well-being, particularly given functional challenges associated with this young adult’s developmental disability and high-risk mental health issues, it was discouraged by professional caregivers. Another mother stated, “We’re trying to find what resources are here . . . all the stupid red tape between [various service providers] and the lack of communication is ridiculous.”

A range of experiences were reported by dually diagnosed individuals and their parents relative to the extent to which health care providers included parents in care, with some parents reportedly treated as peripheral to care. Parents commented that this approach often did not sufficiently address the care needs of their daughter or son. A parent exemplified this challenge by reflecting on recent diagnostic information that lacked parental input which, in her view, impeded an accurate appraisal: “The symptoms that they see are all, to us, attributable to fetal alcohol spectrum disorder—to the brain damage. (But a diagnosis of) schizophrenia? We have never seen any negative or positive symptoms of schizophrenia . . . ”

Parents generally reported gaps in professional engagement with parents and a periodic lack of interest in parental/family experience; a parent reported needing “some empathy and understanding” which she felt was lacking. This participant stated, “What we really seem to struggle with is the physicians who don’t seem to have any understanding.” Another parent indicated that rather than a requested face-to-face meeting,

The psychiatrist left a voicemail on my machine, saying that it was too bad that he wasn’t going to be able to meet with concerned parents; like, wow! Can you imagine? Like, they have no idea of what advocacy we’ve done, and so to make a blanket statement like that is just so hurtful, and it just makes you want to just “freaking” give up.

Some parents reported feeling pressure from health care professionals to become less involved with their adult child: “[Health care providers] felt that we should give that [involvement in care] up so that I wouldn’t be so involved and stuff, which I don’t feel was a very fair statement to me.” Another participant described similar messaging as “a slap in the face.”

In the face of dismissive messages to parents, several participants felt that available community and institutional care staffing was insufficient relative to the complex needs of dually diagnosed persons; hence, parents perceived no choice but to remain actively involved in care. A lack of alternative care was illustrated by a young adult with a dual diagnosis:

Because of the way the system is, there’s not enough nurses to provide the proper patient care, so I end up having a lot of other people come in and do a lot of stuff for me. I have friends that come in and help me to shower, help change my bedding and do those sorts of things, because there’s just not people there to do it.

A participant with a dual diagnosis reflected on his experience relative to a perceived lack of care in hospital after a severe mental health episode: “. . . the nurses were really
busy most of the time with other patients." A parent described challenges with resources only providing service for a limited amount of time (e.g., holding suicidal persons for only a predetermined maximum amount of time) which was felt sometimes to be insufficient relative to presenting needs for care and monitoring, and often reverted to care by parents. A parent concluded in frustration: “There’s nothing out there, or very little, for mental illness.” Another parent emphatically stated, “Why don’t we have a mental health worker? Get us a mental health worker. I don’t know why we don’t have one; [my adult child] has mental health problems [with emphasis].”

Despite most participants with a dual diagnosis reportedly having the ability and desire to be employed or involved in other daily vocational activity (e.g., having skills and aptitudes for paid employment or volunteer activity), they generally lacked social and vocational engagement in the community. Existing resources were typically reported as limited, with individuals with a dual diagnosis primarily and/or intermittently depending on their families (i.e., parents) for support with community/vocational participation.

With identified gaps in community care access, parents expressed concern about the safety and well-being of their adult child in the community without their support as well as uncertainty and fear about that individual’s future. A parent shared, “If we don’t try to help these young people today, where are they twenty years from now? If he doesn’t get the help and support he needs, where will that lead him?” Another added, “It worries me that too many people with mental illness are out with no help and resources.”

Overall, participants described a lack of continuity of care such that individuals with a dual diagnosis tended to be “bounced” between programs and family care due to the misalignment of services relative to individual needs: “Consistently, an agency will take him and say, ‘We’ll never give up on him.’ I cannot tell you how many times I’ve heard that, and then within about 3 months, they are wanting him to move.” Another added, “We have no supports. We have each other [parents], that’s all we have.” Another parent added, “[My daughter with a dual diagnosis] has had to have supports every day, and I find that if people don’t have supports in the long-term, they give up, and when the parents give up, who do these people have?”

**Supportive Care**

Despite multiple negative experiences associated with a dual diagnosis, participants relayed instances of positive and helpful interactions with care providers and programs. Examples included a mental health/support worker who organized appointments and transportation on behalf of a dually diagnosed participant, targeted support groups in the community, activities at the hospital, and staff who reminded participants of upcoming appointments. An individual with a dual diagnosis illustrated a positive experience:

If you’re struggling out there, can’t talk to any of your friends, go to the walk-in clinic and talk. Or even up to the hospital, they have people that talk to you. Because if it wasn’t for them helping me through last year, I don’t know where I would have been.

Multiple instances of valued care offered by health care and service providers were identified. Parents relayed with gratitude; accommodations made for their children’s unique needs, including allowing absences from programs that are normally not allowed; or college personnel working to keep the adult child enrolled in an educational program despite risk of discipline or expulsion.

Another parent shared that a staff member helped her to better advocate for services: “The social worker has helped me ‘go to bat’ [in advocating] that he has to stay until there can be a home found for him, and they’ve tried their best to do that.” Such instances of support were appreciated, with parents often hoping to retain such care providers.

**Discussion**

Participants largely identified a preponderance of personal and family challenges with services and support. These findings are consistent with previous studies that convey challenges faced by families (James, 2012). In a recent review of research related to the experiences of carers of family members with intellectual delay and challenging behavior, James (2012) concludes that family carers often receive insufficient support. These concerning findings appear consistent with emerging research identifying gaps; for instance, one study reports that among parents of adult children with intellectual disabilities and mental health issues with behavioral challenges, “mental health services were rated as needed by all of them, received by 81% of them, and rated as not effective by 94% of those who received it” (Weiss & Lunskey, 2010, p. 155).

Findings from parents in the current study add contextual detail and depth to their adult daughter’s or son’s account of his or her difficult experiences and care-related processes (and vice versa). Accordingly, we had hoped that the inclusion of the perspectives of both individuals with a dual diagnosis and their parents/informal caregivers would thicken description, with groups cumulatively contributing to the development of emergent themes. As an example of corroboration, both groups indicated that parents and other informal caregivers largely absorb system deficits by navigating the system and providing ongoing care and advocacy. It is recognized that parents often are relied upon for, and critical to, care in their role of an advocate and service provider; however, these findings ironically render parents as sometimes dismissed within care systems. Notwithstanding an individual’s right to privacy, health care providers and systems of care must consider heightened family-centered care that more effectively supports individuals and families.
An adequate compendium of resources is needed such as
community housing, vocational engagement, recreation, and
transportation as well as health and mental health services
(prevention, community care, emergency care, acute care,
and post-acute stabilization), with capacity in developmental
disability. Accordingly, the enhancement of publicly funded
services is strongly recommended in advancing a holistic
and sufficiently resourced system of care that effectively
addresses the needs of people with developmental disability
and mental illness.

James (2012) reports that family carers value accessible
information and ongoing support from professionals. This
invites a range of support services, potentially including case
management, education, and navigational support for fami-
lies. Participants in this study identified gains when receiv-
ing helpful and respectful professional and paraprofessional
care and assistance with tangible needs such as navigation,
transportation, and support. These services emerge as ele-
mental to a comprehensive system of care—a standard of
care that was variably absent for participants in this study.

Capacity building for professional/paraprofessional
health and social care providers is needed, including ongoing
education opportunities, resources, and standards of practice
(e.g., acute/institutional care, proactive community sup-
ports). Specialized university/college training is warranted
for health/mental health as well as community/social service
providers. This requires greater understanding of firsthand
experiences and needs of individuals and families, along
with concrete strategies to guide practice and programs. As
noted above, incorporating community navigators is war-
ranted to advocate for, and optimize access to, services for
dually diagnosed individuals and their families. Furthermore,
training is needed for first responders (e.g., police, ambu-
ance/emergency personnel, and emergency room staff).
Developmental medicine tends to be based in pediatrics,
with less focus on adult-based developmental disability and
mental health. Greater focus is needed on how these diagno-
ses intersect and affect the individual and family across the
life span which invites heightened research and university-
based developmental health/mental health and disability
training as well as ongoing professional development.

Limitations and Recommendations for
Further Study

The study was exploratory and reflected a relatively small
sample size, although reasonable by qualitative inquiry
standards. For instance, Hagaman and Wutich (2017) argue
that saturation tends to be reached in a homogeneous popu-
lation with a qualitative sample of 12 to 16 individuals.
However, this sample did not represent the wide breadth of
potential severities and complexities inherent in a noncate-
gorical developmental disability and mental health context.
Further depth of study across conditions is recommended.
Another limitation consists of a lack of precision in sampled
participants’ (with a developmental disability) functional
ability and IQ. Further study is invited that differentiates
functional level and mental health expression relative to
experiences and outcomes.

It is important to note that recruitment in this study was
challenged by a lack of system-wide surveillance of cases of
dual diagnosis. Accordingly, many care recipients potentially
may be lost to proactive follow-up or not readily identifiable
for research involvement. Finding ways to identify this pop-
ulation and bolster representation emerges as important in
amplifying needs, experiences, and outcomes. Furthermore,
examining the confounding impacts of the social determin-
ants of health (e.g., minority ethnicity, lower socioeconomic
status, housing insufficiency, and rural home location) is rec-
commended, as are developing and testing proactive health
and community care interventions including promising mod-
els of person- and family-centered care.

Conclusion

This study has illuminated care-related experiences among
adults with a dual diagnosis, and their families. Without
resources to ensure timely and comprehensive access to care
as well as coordination and quality of that care, individuals
and their families remain at risk for continued struggle and
suboptimal outcomes. In contrast, a holistic, integrated sys-
tem of care has the potential to nurture improved care experi-
ences and outcomes—an important aim in seeking health
and social care effectiveness and ultimately individual and
family quality of life.

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References

Azimi, K., Modi, M., Hurlbut, J., & Lunsy, Y. (2016). Occurrence
of medical concerns in psychiatric outpatients with intellectual
disabilities. Journal of Mental Health Research in Intellectual
Disabilities, 9, 24–35. doi:10.1080/19315864.2015.1108377
Bhaumik, S., Tyrer, F. C., McGrother, C., & Gnaghadaran, S. K.
(2008). Psychiatric service use and psychiatric disorders in
adults with intellectual disabilities. Journal of Intellectual
Disability Research, 52, 986–995. doi:10.1111/j.1365-
2788.2008.01124.x
Bielska, I. A., Ouellette-Kuntz, H., & Hunter, D. (2012). Using national surveys for mental health surveillance of individuals with intellectual disabilities in Canada. *Chronic Diseases and Injuries in Canada, 32*, 194–199. Retrieved from http://www.phac-aspc.gc.ca/publicat/hcdispsm/hcdispsm-cat-g.html

Bongiorno, F. P. (1996). Dual diagnosis: Developmental disability complicated by mental illnesses. *Southern Medical Journal, 89*, 1142–1146.

Bowman, R. A., Scotti, J. R., & Morris, T. L. (2010). Sexual abuse prevention: A training program for developmental disabilities service providers. *Journal of Child Sexual Abuse, 19*, 119–127. doi:10.1080/10538711003614718

Centre for Addiction and Mental Health. (2012). *Dual diagnosis*. Retrieved from http://www.camh.ca/en/hospital/health_information/a_z_mental_health_and_addiction_information/dual_diagnosis/Pages/default.aspx

Cooper, S., Smiley, E., Morrison, A. W., & 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.bp.106.022483

Davis, E., Barnhill, L. J., & Saeed, S. A. (2008). Treatment models for treating patients with combined mental illness and developmental disability. *Psychiatric Quarterly, 79*, 205–223. doi:10.1007/s11126-008-9082-2

Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual & Developmental Disability, 36*, 137–143. doi:10.1080/13668250.2011.572548

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*, 166–174. doi:10.1111/j.1741-1130.2012.00347.x

Government of Alberta. (2000). *Persons with Developmental Disabilities Services Act* (R. S. A. 2000, c P-9.5). Edmonton: Alberta Queen’s Printer.

Hagaman, A. K., & Wutich, A. (2017). How many interviews are enough to identify metathemes in multisited and cross-cultural research? Another perspective on Guest, Bunce, and Johnson’s interpretive description: Qualitative research for applied practice (2nd ed.). New York: Routledge.

James, N. (2012). The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: What do carers say? *Journal of Intellectual Disabilities, 17*, 6–23. doi:10.1177/1744629512472610

Jones, J. L., Gallus, K. L., Vering, K. L., & Osland, L. M. (2015). “Are you by chance on the spectrum?” Adolescents with autism spectrum disorder making sense of their diagnoses. *Disability & Society, 30*, 1490–1504. doi:10.1080/09687599.2015.1108902

Kwok, H. W. (2001). Development of a specialized psychiatric service for people with learning disabilities and mental health problems: Report of a project from Kwai Chung Hospital, Hong Kong. *British Journal of Learning Disabilities, 29*, 22–25. doi:10.1046/j.1468-3156.2001.00095.x

Lunsky, Y., Balogh, R. S., Cobigo, V., Isaacs, B. J., Lin, E., & Ouellette-Kuntz, H. M. J. (2013). Primary care of adults with developmental disabilities in Ontario: An overview. In Y. Lunsky, J. E. Klein-Geltink, & E. A. Yates (Eds.), *atlas on the primary care of adults with developmental disabilities in Ontario* (pp. 5–17). Ontario: Institute for Clinical Evaluative Sciences.

Maes, B., Broekman, T. G., Dosen, A., & Nauts, J. (2003). Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research, 47*, 447–455. doi:10.1046/j.1365-2788.2003.00513.x

McIntyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disability: The impact on families. *Journal of Intellectual Disability Research, 46*, 239–249. doi:10.1046/j.1365-2788.2002.00371.x

Moss, S., Bouras, N., & Holt, G. (2000). Mental health services for people with intellectual disability: A conceptual framework. *Journal of Intellectual Disability Research, 44*, 97–107. doi:10.1046/j.1365-2788.2000.00283.x

National Research Council. (2014). *The growth of incarceration in the United States: Exploring causes and consequences*. Washington, DC: The National Academies Press.

QSR International. (2012). NVivo (Version 10). [Computer software]. Retrieved from http://www.qsrinternational.com/products_nvivo.aspx

Raghavan, R., & Patel, P. R. (2008). *Learning disabilities and mental health: A nursing perspective*. Oxford, UK: Blackwell.

Rose, N., Kent, S., & Rose, J. (2012). Health professionals’ attitudes and emotions towards working with adults with intellectual disability (ID) and mental ill health. *Journal of Intellectual Disability Research, 56*, 854–864. doi:10.1111/j.1365-2788.2011.01476.x

Salvador-Carulla, L., Martínez-Leal, R., Heyler, C., Alvarez-Galvez, J., Veenstra, M. Y., García-Ibáñez, J., . . . Van Schrojenstein Lantman-De Valk, H. M. (2015). Training on intellectual disability in health sciences: The European perspective. *International Journal of Developmental Disabilities, 61*, 20–31. doi:10.1179/2047387713Y.0000000027

Substance Abuse and Mental Health Services Administration. (2010). *Mental health, United States, 2010*. Retrieved from http://archive.samhsa.gov/data/2k12/MHUS2010/MHUS-2010.pdf

Sullivan, W. F., Berg, J. M., Bradley, E., Cheetham, T., Denton, R., Heng, J., . . . McMillan, S. (2011). Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Canadian Family Physician, 57*, 541–553. Retrieved from http://www.cfp.ca/

Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (2nd ed.). New York: Routledge.

Thorne, S., Reimer Kirkham, S., & O’Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*, 1–21. Retrieved from http://journals.sagepub.com/home/ijq

Trollor, J. (2014). Making mental health services accessible to people with an intellectual disability. *Australian and New Zealand Journal of Psychiatry, 48*, 395–398. doi:10.1177/0004867414531628

Venville, A., Sawyer, A. M., Long, M., Edwards, N., & Hair, S. (2015). Supporting people with an intellectual disability and mental health problems: A scoping review of what they say
about service provision. *Journal of Mental Health Research in Intellectual Disabilities*, 8, 186–212. doi:10.1080/19315864.2015.1069912

Weeks, L. E., Nilsson, T., Bryanton, O., & Kozma, A. (2009). Current and future concerns of older parents of sons and daughters with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 180–188. doi:10.1111/j.1741-1130.2009.00222.x

Weiss, J., & Lunsky, Y. (2010). Service utilization patterns in parents of youth and adults with intellectual disability who experienced behavioral crisis. *Journal of Mental Health Research in Intellectual Disabilities*, 3, 145–163. doi:10.1080/19315864.2010.490617

World Health Organization. (2002). *Towards a common language for functioning, disability and health ICF—The International Classification of Functioning, Disability and Health (WHO/EIP/GPE/CAS/01.3)*. Retrieved from http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf

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