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.

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. Lunsky 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 (Bielska, Ouellette-Kuntz, & Hunter, 2012), Australia (Trollor, 2014), and the United Kingdom (Bhaumik, Tyrer, McGrother, & Gnaghadaran, 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, & Lunsky, 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

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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

Table 1. Individuals With a Dual Diagnosis.

Sex	Home 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

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.

Dually diagnosed individuals and their parents reported being subjected to misunderstanding and/or an overly narrow or simplistic understanding from others as well as an insufficiently focused care plan which was viewed to reflect negative stereotypes and/or a lack of care provider knowledge or system capacity. For instance, an individual with a dual diagnosis stated that his support worker focused on his developmental disability without acknowledging or addressing his mental illness. This individual noted that there is "no dealing with anxiety or the, I guess, lesser mental illnesses." Another young person similarly reflected on what he viewed as singular attention given to only a component of his range of issues which included substance abuse: "They [service providers] just look at the drug and alcohol use; they don't look at what the underlying issue is."

Participants variably reported feeling frustrated, demeaned, misunderstood, and overall unwelcome in their community.

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

couldn't control him, and he just couldn't get past it." According to another caregiver, "Because he was an adult, I couldn't force him to do a lot of things. Then he started to talk about death . . . "

In addressing these issues and supporting their loved one with a dual diagnosis, families were conveyed as devoted to the individual and providing their care despite personal and family struggles in providing that care. They often managed this care based on a reorganization of family life and daily activity, as illustrated by a mother who reflected on her son with a dual diagnosis: "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 or providing direct daily care for her son. She described a recent experience of being extremely "burnt out" and thus missing a care planning/coordination meeting; however, she later determined that she could not afford to miss a meeting as her decision not to be at that session "came back to bite me." In a similar vein, another parent described continual struggle even during hospitalizations:

> Once they admit him [to the hospital], then . . . my life sort of comes to a standstill as I make sure that they keep him, which just seems ludicrous. . . . I've got a full-time job, my husband has a full-time job; you can't just put your life on hold all the time and pay attention to this family member. But you have to, or you quickly know that life will spiral out of control.

Participants reported that a dual diagnosis entailed multiple assessments yet diagnostic confusion. Referring to her adult child's diagnostic trajectory, a parent stated, "He's . . . had many, many admissions into [a health care facility], and

almost with every admission, he gets another diagnosis." New diagnoses often resulted in established routines being changed due to adjustments in medications and care regime, which one parent described as "a complete mess" and confusing for her and her adult son. Reporting her difficulty in obtaining age-appropriate services for her daughter, a parent reflected,

> My family doctor is not feeling comfortable because [the 18 year old with a dual diagnosis] is an adult. He [the doctor] doesn't feel comfortable sending her to somebody that's an adult [care provider]. He still wants to send her to a pediatrician. So now again, she's falling through the cracks because she's now an adult. . . . Like, what do you do?

Parents reported multiple attempts to convince a resistant son or daughter to accept needed services. Both individuals with a dual diagnosis and parents described further struggle due to a lack of services in their community. Such situations caused substantial worry and family struggle because of heightened risk for poor outcomes:

> You're in for hell if there isn't a plan. If there isn't an agency that's going to take him and provide services . . . you're "hooped." You're just, like, what do you do, because you don't want to leave him homeless, but you can't have him in your home either.

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 change, 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 & Lunsky, 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 families. Participants in this study identified gains when receiving helpful and respectful professional and paraprofessional care and assistance with tangible needs such as navigation, transportation, and support. These services emerge as elemental 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 supports). 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 warranted 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, ambulance/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 diagnoses 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 population 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 noncategorical 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 population and bolster representation emerges as important in amplifying needs, experiences, and outcomes. Furthermore, examining the confounding impacts of the social determinants of health (e.g., minority ethnicity, lower socioeconomic status, housing insufficiency, and rural home location) is recommended, as are developing and testing proactive health and community care interventions including promising models 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 system of care has the potential to nurture improved care experiences and outcomes—an important aim in seeking health and social care effectiveness and ultimately individual and family quality of life.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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