Inclusion

Experiences of Parents of Young Adults with Disabilities and Co-Occurring Mental Health Disorders
--Manuscript Draft--

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Abstract

The purpose of this study was to understand the experiences of parents of young adults (YAs) with disabilities (e.g., IDD, ASD) and co-occurring mental health disorders (D/MH). As YAs with D/MH transition out of high school, they experience decreased levels of formalized support. As a result, parents often become primary providers of support. Unfortunately, little is known about the experiences of parents of YA with D/MH, including challenges they face and supports and services they consider helpful.

The researchers used a basic interpretive approach to analyze qualitative data from parents of YAs with D/MH. Participants described: (a) experience seeking diagnoses for YAs, (b) impact of YA needs, (c) parent needs, and (d) recommendations for professionals and other parents. Implications for practice include the need for greater collaboration and training between school and mental health professionals to support YAs with D/MH and the provision of mental health training to professionals and families. Future research should explore the experiences of entire family units to determine coping strategies used across family members.

Keywords. disability, mental health, parents, transition, young adult

Experiences of Parents of Young Adults with Disabilities and Co-Occurring Mental Health

Disorders

Young adults with disabilities are diagnosed with co-occurring mental health disorders such as depression, generalized anxiety disorder, and bipolar disorder at higher rates than their non-disabled peers (Blake, 2017; Poppen et al., 2016). For example, individuals with Intellectual and Developmental Disabilities (IDD) are three to four times more likely to have a co-occurring mental health diagnosis than their typically developing peers (Munir, 2016). Researchers also estimate that approximately 54% of young adults with Autism Spectrum Disorder (ASD) develop depression, experience reduced coping abilities, and an increased risk of suicidal behavior (Mackay et al., 2017). However, this estimate likely underrepresents the prevalence of mental health needs among this population, as it is primarily based on individuals with mild Intellectual Disability due to the difficulty of assessing mental health in those with more severe cognitive disabilities (Wark, 2012). Moreover, research indicates that individuals with other disabilities such as Learning Disabilities and Attention Deficit Hyperactivity Disorder experience mental health challenges (e.g., anxiety, depression, and suicidal ideations; Piers & Duquette, 2016) at higher rates than their non-disabled peers (Blake, 2017; Milligan et al., 2015; Poppen et al., 2016).

Young adults (YAs) who experience a disability and co-occurring mental health disorder (D/MH) frequently experience self-doubt, difficulty developing relationships, and are more likely to engage in aggression, self-harm, or risky behavior (Berszán, 2017; Blake, 2017; Thornton et al., 2017). Given documented disability and mental health-related needs, YAs with D/MH often require greater levels of ongoing academic and individualized support (Florez & Bethay, 2017; Poppen et al., 2016). Additionally, mental health interventions found to be

effective for YAs with mental health disorders are often not flexible enough to meet the highly individualized needs of YAs with IDD or ASD. Such needs may include complex cognitive or communication needs (e.g., use of augmentative or alternative communication devices, delayed processing time; (Milligan et al., 2015). Unsurprisingly, although there is a growing body of literature related to negative outcomes associated with a lack of appropriate mental health support among YAs, there is a lack of research focused on practices to improve mental health among YAs with D/MH (Al-Yagon, 2015; Poppen et al., 2016) including IDD, ASD and other disability diagnoses.

In addition to the lack of research-based mental health interventions for YAs with D/MH, there is a paucity of research that examines the experiences of parents of YAs with D/MH (Benzies et al., 2013). This is important, because as family systems theory (Allen & Henderson, 2017) postulates, families must be examined and understood as a complete unit. As a result, examining the needs of YAs with D/MH through family systems theory posits that one must investigate an individuals' family in order to truly understand YAs, their needs, and what matters in their lives. This is especially true among YAs with D/MH, as they typically begin to seek more independence and privacy from their families and are expected to take on more responsibility for their actions and outcomes (Munir, 2016). However, for YAs with IDD and ASD, family members often continue to play a critical role in providing various forms of academic, financial, logic, and emotional support (Maxey & Beckert, 2016).

For some YAs with D/MH who have IDD, ASD, or other significant support needs, decisions related to guardianship/conservatorship (e.g., a family member being appointed by a court to manage personal affairs of a YA), Family Education Rights and Privacy Act (FERPA, 1974) Waivers (e.g., YAs providing the right for chosen family members to access academic

records), and Health Insurance Portability and Accountability Act (HIPAA, 1996) Waivers (e.g., YAs providing the right for chosen family members to access academic records) are also necessary so that families may provide YAs support, as appropriate and necessary. Moreover, many families must consider short and longer-term access to services and supports related to IDD or ASD and YA mental health needs, potentially including plans to ensure that YAs with D/MH continue to thrive with a high quality of life after primary caregiver death (Seltzer et al., 2012; Taggart & McConkey, 2012).

Exploring the experiences of parents of YAs with D/MH is important, given the critical and ongoing support they provide to their YAs (Francis et al., 2019; Heifetz & Dyson, 2016; Milligan et al., 2015). In addition, examining the experiences of parents of YAs with D/MH could provide information that enhances practice, professional and family training, and specific strategies that could be used to enhance well-being for YAs with D/MH and their families. Therefore, the purpose of this study was to examine the experiences of parents of YAs with D/MH by answering the following research question: (1) What are the experiences of parents of YAs with D/MH?

Methods

The researchers used a basic interpretative qualitative design for this study (Merriam & Tisdell, 2016). The principal investigators (two white, English-speaking, female special education faculty members) used convenience sampling procedures to recruit participants. Criteria for recruitment and purposive selection included (a) parent or primary caregiver of a YA aged 15-30 years with a diagnosed disability and mental health disorder/need and (b) consent to audio record the conversation. This study received university IRB approval prior to recruitment and data collection.

The principal investigators sent a recruitment email to approximately 20 parents of YAs with D/MH they knew through personal (e.g., friends of family) or professional interactions (e.g., coworkers, staff from family organizations). They engaged in this sampling technique given the sensitive nature recruiting parents of YAs with D/MH (e.g., cultural perspectives regarding D/MH, stigma related to D/MH; Cai & Richdale, 2016) and because these participants all previously openly discussed their experiences supporting their YAs with D/MH. The recruitment email described the study, included a link to a confidential Doodle poll to schedule focus groups or interviews (participants were asked to select their preference), and provided contact information for the investigators. Interested participants completed the Doodle poll to indicate their interest in participating in a focus group or one-on-one interviews, as well as their availability. A total of eight parents responded with interest into participating in this study.

Participants

Seven of the eight parents of YAs with D/MH we recruited agreed to participate in a focus group (n=5) or interview (*n*=2). Prior to engaging in conversations, all participants completed a basic demographic questionnaire. Six participants identified as White/Caucasian and one participant identified as Black/African American. One participant identified as male and six identified as female. Three participants indicated that they were over 56 years old, two were between 46 and 50 years old, and two participants indicated that they were between 41 and 45 years.

Participants' YA's primary disabilities diagnoses varied, with three participants having YA with IDD, one with multiple disabilities including IDD, two with ASD, two with Other Health Impairment (ADHD) and one each with Emotional Disability and Specific Learning Disability.

Gathering data on participants' YA's primary mental health diagnoses was challenging, as one participant was not comfortable disclosing, and another reported that she believes that her son had Bipolar Disorder although he never received a formal diagnosis. Four other participants reported that their YA had diagnoses of Bipolar Disorder, including one with Bipolar Schizoaffective Disorder. Three participants reported that their YA had other mental health diagnoses including one with a diagnosis of Schizophrenia, one with Post-Traumatic Stress Disorder (PTSD) and one with Generalized Anxiety Disorder (GAD).

One participant (Cassie) richly described, but elected not to disclose their children's mental health disorders. Another participant (Angela) was unable to secure a formal diagnosis for their child, but described her son's mental health needs and suspicion of a mental health disorder. Further, another participant's son was deceased at the time of the interview. However, this participant (Lola) felt a strong commitment to sharing her story via this study, given the profound impact that her son's disability and mental health disorder had on her family- including her son's death and her daughter's development. Table 1 provides additional participant demographics, including YA's diagnoses and all participants' names were replaced with pseudonyms.

Data Collection

The research team (i.e., the principal investigators and a white, English-speaking, female graduate research assistant studying higher education policy) used a basic interpretative approach (Patton, 2002) to conduct and analyze focus group and interview data. The team conducted one focus group in person in a private room on a college campus with five participants. The focus group lasted approximately 90 minutes. Two interviews were conducted via telephone with participants who lived out of state. Interviews lasted approximately 60 minutes.

When collecting data, the principal investigators first reviewed the purpose of the study as well as risks and benefits of participation before seeking written consent. The research team collected data using a semi-structured protocol, developed from previous research on YA D/MH mental health that included YAs and professionals as participants (e.g., Francis et al., 2019; Fujita et al., in press). This literature informed the focus of the questions (e.g., a focus on MH barriers and strategies, exploring MH experiences across environments). The protocol included questions related to participants' (a) positive experiences related to disability and mental health support at school, home, and in the community (e.g., Tell us about your experiences related to mental health and individuals with disabilities.); (b) negative experiences related to disability and mental health support at school, home, and in the community (e.g., What barriers have you experienced related to effective mental health support to adolescents and young adults with disabilities?); (c) coping strategies participants used to support their YA's mental health (e.g., Talk to us about some effective mental health strategies you've used or heard about.); and (d) recommendations to improve disability and mental health support for YAs with D/MH (e.g., What would ideal mental health support look like for adolescents and young adults with disabilities?).

One principal investigator facilitated the focus group while the other members of the research team took field notes about the discussion, including key points, questions, tone, and body language. One principal investigator also facilitated the two interviews with the out-of-state participants. The research team concluded the focus group and interviews with member checks by using field notes to review major ideas and events with participants and inviting them to correct or expand on information. Some participants expanded on information during the member checking process (e.g., provided more information about physician disposition, provided

more detail on how teachers made them feel during meetings), but no participants corrected

themes or information presented. The research team also met after the focus group and

interviews to discuss and record research memos on emerging themes.

Analysis

A professional transcriptionist transcribed all recorded data. The graduate research

assistant then read through transcripts while listening to audio recordings to (a) de-identify

transcripts, (b) get a general sense of the data, and (c) confirm transcription accuracy (Creswell,

2009). The research team began data analysis by collaborating to open code the data. The team

first independently read a single transcript to determine keywords and descriptive categories

represented in the data. Next, the team debriefed to identify similarities and differences among

the open codes and developed an initial codebook based on this discussion (Creswell, 2009). The

research team then used the initial codebook as a guide to independently read and hand-code

another transcript, before meeting again to discuss subthemes under each category, identify

unique or irrelevant topics, and develop rich descriptions of each subtheme. This process resulted

in a third and finalized codebook. One principal investigator used the finalized codebook and

NVivo qualitative software (QSR International, 2020) to recode all transcripts. However, the

research team continued to meet weekly until all data were analyzed to debrief about analysis

procedures and ensure consensus regarding all codes and categories. No new categories or

themes emerged during this time.

Trustworthiness

The research team employed several measures to ensure the credibility of data collection

and analysis procedures. Initial trustworthiness procedures occurred during interviews, as the

research team (a) encouraged participants to command the discussion through the use of open-

ended questions and prompts, (b) recorded conversations to gather precise information, (c) used field notes to conduct member checks, and (d) wrote researcher memos immediately after data collection to enhance an understanding of the data (Wolcott, 1990). The research team engaged in three additional trustworthiness procedures during the analysis of data, including (a) comparing written transcripts to original interview recordings to ensure accuracy, (b) using a three-person team approach to transcript analysis, and (c) meeting weekly to review and discuss interpretations of data and discuss potential researcher bias in the analysis (Patton, 2002). Finally, the researchers included rich descriptions of participant data (e.g., direct quotes) to provide adequate evidence of participant context and intent (Merriam & Tisdell, 2016).

Findings

While discussing their experiences, participants described: (a) experience seeking diagnoses for YAs, (b) impact of YA needs, (c) parent needs, and (d) recommendations for professionals and other parents of YAs with D/MH.

Experience Seeking Diagnoses for YAs

Participants described the challenge of identifying YA mental health diagnoses due to the intensity and intersectionality of mental health disorders and other disabilities. These missed diagnoses resulted in YAs experiencing unnecessary hardship, as the core of their needs went unaddressed. Marci shared:

> My daughter has intellectual disabilities and physical disabilities. The mental health gets not noticed because everything is attributed to the other disabilities…it's hard to tease out where the mental health is and where the other disability- where those two things meet.

Marci also noted that doctors do not "listen" to parents when they describe the characteristics and behaviors of her YA with IDD and other disabilities in order to determine appropriate

diagnoses. Listening to parents was especially important to Marci because her YA "is not

capable of- she'll say whatever she thinks you want to hear."

Colleen also experienced diagnostic barriers with her son because professionals focused

exclusively on his ASD diagnosis. She expressed her belief that both disabilities and mental

health disorders should always be considered "because autism is not ever just autism." Likewise,

Margaret described how challenging it was to find a physician to provide appropriate diagnoses:

"There's only one doctor here that we can go...anybody else takes months and months [and] you

have to put a $100 deposit down just to make the appointment- and then you only see his

assistant." Margaret also noted that health professionals generally lack information about D/MH

needed to "treat the whole child."

David shared an emotional account about seeking a mental health diagnosis for his

daughter when she started college. Unfortunately, although his family sought professional help

as soon as her mental health symptoms manifested, it took an emergency for her to finally

receive a diagnosis:

> I took her to the E.R. They said it's just nothing. She's just stressed because she's about to
>
> do finals. I go back to [the] school. I tell them…she's just not ADHD [attention deficit
>
> hyperactivity disorder]… [I] tell everyone - the Dean, tell the counselor there - they said
>
> it's okay…it's anxiety separating from high school. Then two weeks later we get a call….
>
> So I'm running down there and come to find out she was bipolar/schizo[phrenia].

Lola, however, experienced the opposite situation, with her son's extensive learning disabilities

going largely unaddressed in school due to behavior associated with his mental health diagnosis.

She noted that individuals like her son who have learning disabilities and severe bipolar "might

have some learning issues that nobody's even seen because [they] can't see through his anger or

whatever."

Impact of YA Needs

Participants described YA D/MH needs impacting their YAs, as well as how YA needs

impacted their families. For example, Colleen shared that her child "suffer[ed] greatly" from

"pretty much everything that comes" with his diagnoses of ASD and schizophrenia, PTSD and

GAD. On the other hand, Marci indicated that despite her daughter's multiple disabilities

including IDD, her "mental health- more than anything else really, *really* impacted our life."

However, all participants generally noted that YA behavior and need for ongoing support greatly

impacted YAs and their families.

YA Behavior

Behaviors related to D/MH, including self-harm and aggression, impacted YA and

family outcomes. For example, David shared that his daughter once "tried to cut herself on her

heart because she said her heart hurt." Colleen also indicated that her son experienced "voices

telling [YA] to do stuff which is super dangerous…and that's a really hard thing and when you

bring them out into the community and if they would have an episode or hear something."

Colleen recalled numerous times that her son turned to self-harm:

> Since those two [overdoses] with 24 pills, he has eaten his deodorant, he's eaten his hand
>
> lotion, he's eaten antibiotic hand cream, progesterone cream. He has eaten a tub of
>
> Aquaphor and all in hopes to die. So all of our lotion, all of our shampoos - anything
>
> liquid in our house is locked up…

Colleen discussed numerous preventative strategies her family took to protect her son

from self-harm, including purchasing "a sealed safe" for the kitchen and "a locked cabinet in the

garage" to prevent access to chemicals and dangerous objects. In addition to self-harm, participants also recalled times when YAs became aggressive. Colleen described such an incident: He almost killed me... I [called] 911 and paged [Husband], and [Husband] came home and he went completely ape shit…it was scary and intense." Margaret's son also experienced aggression from a young age: "I was just putting him in the car seat and he attacked me so violently that I had never seen a baby do that. And I remember thinking, who the heck is this?"

Participants uniformly indicated that puberty and adolescence amplified negative behaviors among their YAs with IDD, ASD, and other D/MH, including aggression, self-harm, and risky behavior (e.g., substance abuse). For example, Colleen recalled that adolescence:

…was a really big awakening… like I thought I had it. I thought we were going to be okay. We were doing really great. And then holy shit…everything you know is different…A regular teenager can't manage all that as you're seeing with your typical kids. They can't manage at all. So multiply it and try to get someone with the mentality of a seven-year old to manage it… it's extremely dangerous.

Similarly, David indicated that his daughter's mental health disorder did not emerge until late adolescence and while Lola's son "was hard from a young age…things got really hard starting in middle school." Margaret also discussed her son's aggression as he aged into adulthood: "This mama is tired and he's getting bigger. He weighs more than I do now so the physical aggression is terrifying and brings a level of anxiety to our home that is overwhelming." In addition, as her son matured into adolescence Margaret realized that "my emotions were affecting him- if I have a bad day, he has a bad day. I'm very cautious about staying on top of my thoughts." Colleen also reported that family members expressing negative emotions (e.g., sadness, exhaustion, disappointment, aggravation) resulted in her YA internalizing the negativity

and engaging in dangerous behavior: "I'm not allowed to say anything. [laughs] I'm not allowed to do anything that is human…[because] his behavior a lot of times is a reaction to ours times 10."

YA Need for Ongoing Family Support

Participants described several YA needs requiring ongoing family support, such as arranging transportation and daytime activities, "daily check-in calls or [making sure] you're physically there because [YA] has to be supervised" (Marci), providing fiscal management, facilitating medication compliance, admitting YAs to treatment centers, soothing YAs while in crisis, and advocating for YAs with school and community professionals.

Other participants described the need to monitor YA behavior for signs of mental health crises. For example, David indicated that he was "always looking for those [mental health] indicators...when she starts getting spacey…she goes manic. And I'm like oh man. I've got to get her to the hospital." Participants also provided ongoing encouragement for their YAs to engage in personal care strategies, including proper nutrition, sleep, and exercise. Angela noted that her family's "life kind of revolves around [meals] – [YA] has to eat every two hours…he can't be hungry, tired, or if he's sick, those are when his outbursts become more likely." Regarding exercise, Colleen reported she had to consistently ensure that her son exercised to manage his anxiety and aggression: "He needs to run. He needs to sweat. And as he says he needs to feel it in his tummy. His tummy needs to be 'jiggly' for him to actually feel the benefit of exercise."

Monitoring medication and dosage compliance also emerged as another area requiring ongoing support from participants. Colleen described the importance of her YA taking his medication: "I give [YA] a dust of risperidone. But he misses it one day it's a difference. All it takes is a speck to make a change that they [YAs] need." For some parents, their YA's

independence made medication compliance and consistency challenging. For instance, Lola reported that her son would feign taking prescribed medication for ADHD and bipolar disorder and later dispose of them in the trash or toilet. David also shared challenges he faced supporting his daughter with her medications:

> I'm always worried about...I'm waiting for that call. I'm looking for sign...because she's going to be on meds for right now. She's been for two years but she's not going to stay on meds. When she starts feeling better she'll get off some.

> Participants also described additional ways that they provided YAs ongoing mental health support. For example, participants did a "lot of pre-managing" (Margaret) by teaching YAs "some strategies to help minimize" crisis situations (Angela), such as "recognizing thoughts" (Cassie), asking for help, taking a break, or engaging in a soothing activity (e.g., deep breathing, exercise, sensory activities, self-talk). Colleen also described numerous ways she continuously prompted her YA to engage in self-soothing techniques such as reminding him to get under his "heavy blanket where he can calm down" and holding "two hands in front of me and say[ing] is this autism or asshole? He'll hit my hand and say oh, this is asshole. He'll tell me. [laughs]." David encouraged his daughter to journal when she experienced mental health crises and then use the journals to reflect on what occurred and strategize next steps once the crises have passed:

> I give her the journals and she'd read it. And she'd be just like in amazement that she was thinking all this stuff. Then we started coming up with strategies. So she goes counseling. As a parent what do I do? We set goals.

Lola also set ongoing goals and incentives to motivate her YA to "get out of bed…I've had to have that carrot for him to give him a goal, to keep him going."

Marci indicated that providing ongoing care and support became a "self-fulfilling prophecy" for many families such as hers: "You're taking care of your kid and so the kid is not in a dire situation…you never get out of that role of always being the support person for your kid. And that's just really a problem." David agreed, "It's like I'm more of a parent now than I was when she was growing up. I'm calling her every single day. I do routine stops." Similarly, Lola described the "odd situation" of providing daily support while also promoting her YA's independence and providing him with opportunities to learn from natural consequences. Lola noted: "If somebody upset him or whatever or he'd just get depressed and lay at home [missing school and work]. You know what? That was okay with me because I knew where he was [home with me]." However, in the end Lola lamented that, despite her ongoing efforts, she "could not protect [YA] from himself."

Parent Needs

Participants described several barriers related to their own needs, including the need for (a) respite care, (b) sibling support, (c) information and guidance, and (d) empathy and confidence.

Respite Care

Participants indicated a need for adequate respite care: "I have to build in breaks because I can't just keep going anymore. It's too intense" (David). Margaret expressed a similar sentiment about raising a YA with D/MH, "It is so exhausting. It's an all-day thing. There's no break now that he's not in school." Angela also expressed a need for respite care, despite being on "a [Medicaid] waiver right now that provides respite for our son but nobody will come at $11.47 an hour!" On the other hand, Margaret noted that while "family support would be wonderful," her family didn't "qualify for any respite or anything." Margaret indicated that a lack of respite was

especially difficult because "I can't leave [YA] alone with my daughter… I can't shower, I can't leave her downstairs…We just can't call a babysitter. People always say to me, why don't you and your husband go out? [Laughter]."

Sibling Support

Margaret and other participants described the disparate ways in which they interacted with their children with and without D/MH: "She's [daughter without D/MH] had to mature so much faster and that's just not fair. Sometimes I find that I have to overdo it for her, like I'm trying to compensate. And she has dyslexia…It would be helpful to have some support [for her, too]." Lola also weighed in: "My daughter gets straight A's and she'd get nothing…I am so sorry..." Lola also described how her daughter would "see me get exhausted [and] would step up. So we were kind of raising [YA] together, I guess. I don't think that's fair but that's kind of how our life went so I kind of feel bad about that." Cassie noted that her oldest son also took on more responsibility than she preferred:

> When he was eight years old, [he] heard us talking about who's going to be guardian of
> [YA] if something happens to us. I heard his little voice in the next room. "That'll be
> me." We did as much as we could to keep it from impinging on him.

Information and Guidance

Participants indicated a need for more information to better support their families and receive appropriate services for their YA with D/MH. For example, Lola highlighted a need for information on how to support her son academically: "I have learning disabilities as well [and] they [teachers] didn't teach me how to help him. So we both kind of fell through the cracks and he suffered pretty much his whole school life because of that." David added that schools

"typically focus on the disabilities [they're] comfortable with…there's not training as a parent"

on how to support the comprehensive needs of YAs with D/MH.

Margaret noted the "big black hole!" of parent knowledge of disability and mental health-

related services:

> I know hundreds of moms- *hundreds* of moms I have connected with that are in the exact
>
> same situation… these families have never been told anything about sensory processing
>
> or mental health. These are the kids who are going to end up in jail. These are the kids
>
> who drop out.

Margaret also indicated that professionals often automatically tell families that YAs with D/MH

"don't qualify" for disability or mental health services and that "medical professionals do not

like for us [parents] to tell them what to do. They don't like when you know more than them. But

unfortunately, that's just true at this point."

Empathy and Confidence

Participants expressed a need for empathic and supportive relationships. For instance,

while information was essential to participants, David stated that he felt hearing "stories" from

other families with YAs with D/MH would "validate what [he is] going through." David also

noted that "even when you have the knowledge or even if you have access to resources, it doesn't

really matter. She's always going to be bipolar. So then you think to yourself, well shit…"

Colleen indicated that "there's a lot of stuff I don't share with everybody...other families have

judged us…I don't have a ton of close special needs moms for that reason." Participants such as

Margaret also described how they "never get the sense that [professionals] really understand or

have any empathy" for families. Moreover, participants often felt "attacked" (Angela) at

Individualized Education Program (IEP) meetings in school (e.g., the IEP meeting is a "trial- and he's getting beat up basically…can't we put the positive in here?!" [Lola]).

Further, Lola noted that "a lot of times the parents are blamed" by professionals for their YA's behavior. Margaret agreed that professionals often question parents about their parenting skills (e.g., "Why can't you control your child?"). For instance, she recalled an "interrogation about our parenting" while attending family therapy. Marci also added that professionals, including educators, frequently spoke to her in a "very condescending [way]- 'Why don't you try a token system?' Do you really think I haven't tried that at this point?!... I always hate it when people are like oh, 'Well why don't you...' and you're like, I tried this…"

Recommendations for Professionals and other Parents of YAs with D/MH

Recommendations for Professionals

Recommendations for professionals included: (a) engage in mental health professional development, (b) provide families information, (c) facilitate meaningful interventions for YAs with D/MH, and (d) cultivate parent support groups.

Engage in Mental Health Professional Development. Participants agreed that "mental health has to be a focus" (Angela) in educational settings, in spite of mental health training not currently being a part of teacher licensure or credentialing. Participants indicated a need for mental health professional development such as "Mental Health First Aid training" (Angela) for K-12 and college education professionals to support "*all*" students. Other participants suggested professional developmental activities such as educators "bring[ing] all the people, the experts, the parents in" (David) and talking to "other schools and doctors" (Cassie) to learn about barriers and successful strategies to address mental health. Participants also noted that professional development should address strategies to diminish stigma associated with mental health: "I think

the fact of now we're acknowledging [mental health] and we're trying to get away from the stigma - it's still going to take decades to effect what to do with it in school." (Lola) Angela added that mental health training and information should extend to students with and without disabilities so they may "see something in themselves or realize this person and what they're going through."

According to participants, professional development activities focused on improving mental health would allow school professionals to "really understand the basics of what a mental health condition looks like" (Cassie), "be a little bit more welcoming and understanding" to students with D/MH (Marci), and "give them [educators] a very immediate strategy and basic steps that can hopefully just become part of the culture from the front office to the cafeteria" (Angela). Participants also suggested that appropriate training would help in "early detection of hidden disabilities" (Lola) such as mental health disorders, Autism Spectrum Disorder, and learning disabilities. Participants agreed that mental health information and strategies would help prevent "assumptions about behavior that they're [YAs with D/MH] just being purposefully difficult or purposefully disruptive" (Marci), and, "in some cases, give our kiddos a little bit of a second chance when a behavior occurs" (Cassie). Participants also agreed that professional development would help destigmatize D/MH and increase socialization opportunities for YAs. However, David noted that "constant reinforcement" of professional development from school administrators is necessary for such efforts to be effective: "I think that that's the only thing that systemically is going to change what's actually going on. You have to bring the experts in but it has to be reinforced through [school] leadership."

Provide Families Information. Similar to professional training, participants also recommended that education professionals engage in a "wider recognition of some mental health

issues" (Angela) to provide families more comprehensive information. Participants provided

several recommendations on how to provide families information about mental health disorders,

services, and supports, including developing a "parent resource page on the [school] website"

(Lola), individually "walking through" mental health and disability resources with families

(Angela), creating a dedicated school-based resource center to inform families about disability

and mental health support organizations, and providing family-centric classes and workshops

about conditions and how to access services after graduation. Marci noted that providing families

with information about services and supports while YAs are in school is critical because "school

isn't the only solution… there are other service systems that our families need to be able to

manage."

Facilitate Meaningful Interventions for YAs With D/MH. Several participants

recommended school-based interventions that could be employed for YAs with D/MH, such as

"peer support" (Marci) to enhance YA well-being and development in inclusive settings.

However, Angela cautioned that "inclusion should be a range" and that instead of focusing on

inclusion for inclusion's sake, professionals should focus on creating meaningful social

opportunities for YAs with D/MH that will result in longer-term relationships and overall well-

being. That said, participants generally recommended that YAs with D/MH should experience

"peer support in mental health [from] someone with a similar lived experience who is generally

at a farther along place with their recovery" (Angela) while in school. Other interventions

participants recommended school professionals utilize included "trauma-informed care to benefit

our kiddos with mental health conditions and other disabilities" (Marci) and teaching "self-

determination and self-advocacy" skills because, "particularly in the mental health field, there's a

real recognition of empowering persons with mental health conditions to really take charge"

(Cassie). Participants also described the importance of educators, counselors, and school administrators working as a "team" (Colleen) to support YAs with D/MH and cooperating with "outside providers" such as (a) "therapeutic day treatment center" staff (Angela), (b) mental health clinicians, (c) case managers, (d) social workers, and (e) therapists to prevent students "being suspended and being blamed" for poor behaviors caused by their disability or mental health conditions (Cassie).

Although recommendations primarily focused on school professionals, Margaret and Colleen also recalled how community professionals, including local police departments and religious leaders, facilitated meaningful interventions for their YAs that could be replicated by others in the community. Margaret described a positive experience when she called the police when her son was "raging, cussing so bad at me, and breaking things downstairs" to let the YA know that "we mean business" and show him "the consequence of his behavior." When the police arrived, they "talked to him for about an hour" and developed a family safety plan. Colleen described a specific officer who specialized in community support for individuals with Autism Spectrum Disorder, who reinforced Colleen's right to engage in self-defense with her YA, after Colleen called 911 for help during one of her YA's aggressive episodes: "[Officer] comes over and she says 'I don't want to come here the day that your mom kicks your ass because your mom will not get in trouble. Because that's called self-defense and she can do whatever she needs to do to protect herself.'" Colleen also recalled a positive intervention at her place worship when her son was repeatedly attempting suicide:

> [Religious Leader] didn't make [YA] say – "Oh you have to say the Act of Contrition
>
> four times." He just listened and then he told [YA] that it's not his time and that God

needs him on Earth and God put him on Earth to do very important work. [YA] felt

happy after that moment because he felt he knew that he was not in trouble.

Cultivate Parent Support Groups. In addition to peer support for YAs with D/MH,

participants also recommended that school professionals cultivate "support groups for parents

[because] hearing parents' stories helps a lot" (David). Marci thought it would be ideal if parent

support groups "would be some place where parents could gather and there would be somebody

to watch [YAs with D/MH] … so parents could actually have opportunities to just socialize as

well as connect with other people who are validating." Margret also agreed that "a parent forum"

would be helpful because hearing from other families "normalizes what you're going through"

and may help provide parents strategies for supporting YAs with D/MH, as well as their other

children with and without D/MH.

Recommendations for Parents of YAs with D/MH

Participants also provided recommendations for other parents of YAs with D/MH,

including (a) educate yourself and share information, (b) find a parent support group, and (b)

engage in self-care.

Educate Yourself and Share Information. Participants recommended that other parents

of YAs with D/MH seek out information and resources from the time their YAs are young "to try

to understand the root of everything" (David) and how their YAs think and feel. Cassie indicated

that parents of YAs inevitably must become "the expert" on understanding their YAs and, as a

result, recommended that parents "read everything- even if you think it doesn't apply to your kids

because it will. One day." Other participants such as Margaret also noted the importance of

sharing information and "personal experiences" with other families and professionals to "have a

better understanding of it and how we can support young adults in society and in school, too."

Find a Parent Support Group. Participants deeply valued and recommended that other parents find a core group of peers with shared experiences to "turn to" (Colleen). Marci noted that a "peer group is powerful- I can sit with these friends and we can talk about the humiliating situations we've been in and heartbreaking ones...and just laugh together. Cry together. We've done all of it." Cassie also recommended parents "learn from other people's experiences- the other parents- [to] validate [your] own humanity." Further, Angela recommended parents communicate with peers to recognize that "you're still a good parent because that's what's going on is you're thinking deep down you're thinking what did I do wrong to bring this about?"

Participants also shared recommendations on how to locate supportive peers. For instance, Cassie described meeting a supportive peer group through her son's activities: "Our son is in Special Olympics and there is also a Special Ed[ucation] Boy Scout Troop… But the real value of both of those activities were not sports and not the badges. It was parent therapy. It was life-changing for us to find our peer group." Likewise, David recommended finding supportive peers through open discourse with coworkers and other acquaintances: "We were very open, my wife and I. We just started talking about [YA] with client for 10 years who has daughter with bipolar and she never even said anything. My wife and [Other Parent] talk a lot now." Other participants recommended that parents locate peer groups by joining activities and organizations in the community they enjoy such as orchestra, kickboxing, walking groups, and social events.

Engage in Self-care. Participants spoke at length about not only "listen[ing] to your heart [because] you know your kids best" (Lola), also "making self-care a priority" (David). Participants recommended many ways to engage in self-care, including "cherishing little moments" (Margaret), "meditating" (David), waking up before the rest of the family to have time to yourself, and "whiskey [laughing]" (Marci)- a recommendation to which David

enthusiastically added, "single barrel! [laughing]." Another form of self-care participants recommended was acceptance: "Just kind of be able to say this is my life. And this is where it is and it's not going to change and how can I move forward" (Margaret). Colleen also recommended other parents "find the love and humor and enjoy whatever stage you're in." Finally, Marci recommended parents of YAs with D/MH "Stop worrying about all this…this is the good part. [laughing] Enjoy yourself!"

Discussion

The purpose of this study was to understand the experiences of parents of YAs with D/MH. Participants described their experiences seeking diagnoses for their YAs, the impact of their YA's needs, and their own needs. They also shared recommendations for professionals, as well as for other parents of YAs with D/MH. Participants described challenges they faced while seeking mental health diagnoses for their YAs with D/MH, including frustration with professionals overlooking YA mental health disorders, resulting in YA mental health needs to going undiagnosed and untreated. In some cases, difficulty finding a clinician who could effectively disaggregate disability from mental health needs and expensive fees were additional barriers to gaining a timely and accurate mental health diagnosis. Frustration and stress expressed by participants reflect existing literature that found that parental stress increases while navigating diagnostic and treatment processes for their children with disabilities (Schiltz et al., 2018).

Participants also described the influence of their YA's needs on their families, including the tremendous impact of YA mental health and the need to manage their YA's complex behaviors including self-harm and aggression. Similarly, Schiltz et al. (2018) reported that parents of children with Autism Spectrum Disorder experienced greater levels of stress than

parents of typically developing children. In addition, this study found various factors, including the severity of their child's disability, challenging behaviors, and emotional regulation and dysregulation, that impact participant stress level. Further, participants such as Margaret and Colleen emphasized how their own emotions strongly impacted the emotions and behavior of their YAs. Figure 1 displays this loop of the influence of parent mental health on YA behavior, which, in turn influenced parent mental health and the "self-fulfilling prophecy" of providing intensive, ongoing support to YAs. These experiences echo previous findings of researchers who found that parent emotional and mental health impacted child well-being among families of children with disabilities (Anclair & Hiltunen, 2014; Schiltz et al., 2018).

In addition to challenging and sometimes dangerous YA behaviors, participants shared accounts of their ongoing, potentially lifelong roles in YA lives. Participants reported needing to continuously support their YAs (e.g., ensuring YAs take medication as directed by a physician, sleep, use coping strategies), but were ultimately "waiting for that call" for YA mental health crises to occur. Participants also recognized the toll that long-term caregiving took on parents of YAs with D/MH and desired their YAs to be as independent as possible. Previous research has also indicated that parents of children with disabilities feel uncertain about their children's future (including how their children would cope with potential challenges), resulting in enhanced parental stress (Anclair & Hiltunen, 2014).

All participants relied on support from family (e.g., spouses, other children without D/MH), friends, and professionals, which is consistent with research on family resilience (Bayat, 2007; McConnell et al., 2014). However, participants found the support provided from other parents of YAs with D/MH most valuable. Participants also described making these important parent-to-parent connections through YA activities or in other social situations (e.g., walking

groups). These experiences reflect those of parents of YAs with Intellectual Disability who reported developing their own informal support networks of family and friends, including other parents of YAs with similar needs, after their YAs transitioned out of the K-12 school system (Beighton & Wills, 2017; McKenzie et al., 2017). Young et al. (2017) also found that parents of YAs with Intellectual Disability and Developmental Disabilities connected with each other for personal support, to share and validate their experiences, and to problem solve.

Moreover, participants provided recommendations for professionals and other parents of YAs with D/MH. For example, they suggested that professionals participate in professional development activities to recognize the signs of mental health needs among students with disabilities and gain knowledge of mental local health resources. Participants also recommended that professionals provide meaningful interventions for YAs (e.g., inclusion, peer support) and support groups for parents to reduce feelings of helplessness and isolation. Participant recommendations for other parents focused on ways to manage stress and anxiety and increase parent well-being, such as regular self-care practice (e.g., meditation, connecting with other parents, exercise). Some researchers have begun to investigate stress management interventions among parents of YAs with disabilities, including Lunksy and colleagues (2017), who found that a mindfulness meditation intervention for parents of adults with Autism Spectrum Disorder and Developmental Disabilities decreased chronic stress and increased the parents' feelings of life satisfaction.

In addition to reinforcing existing literature, findings from this study contribute new information to the field. First, this study adds to a limited body of literature focused on the experiences of parents of YAs with differing D/MH diagnoses, including YAs with more significant support needs (see Table 1). The experiences that participants shared demonstrate the

complexity and variety of factors that impact YA lives, including mental health diagnosis, disability, and puberty. As a result, participants highlighted the need for enhanced diagnostic processes and procedures to identify and address mental health disorders in isolation from other disability diagnoses. Moreover, participants consistently prioritized needs related to their YA's mental health diagnoses, as opposed to YAs other primary disabilities (e.g., autism, cerebral palsy). In addition, participants also discussed their own psychological needs, indicating the importance of emotional support to enable parents to appropriately utilize information and resources for their YAs, and, as Colleen and Margaret emphasized, maintain their own well-being to allow them to positively influence the well-being of their YAs. Although the ages of YAs ranged from 15-28 years, participants gravitated toward discussing and providing recommendations for education professionals, including that "mental health has to be a focus" in schools. This finding reinforces the profound influence of educators on YA and family outcomes, the importance of early intervention for YAs with D/MH, and the significance of comprehensive mental health interventions being available to all students in school settings.

Limitations

There are three primary limitations to this study. First, although qualitative research is not intended to be generalized across populations (Bogdan & Biklen, 2007), sampling techniques used resulted in a small sample of relatively homogenous participants (see Table 1). Although some methodologists contend that data saturation is not always the aim in phenomenological research (Saunders et al., 2017), this lack of diverse participants diminishes the likelihood that study themes reflect the experiences of large numbers of parents of YAs with D/MH. Second, participants self-reported all diagnoses (incluand the researchers did not collect data on the severity of D/MH. In addition, the researchers did not gather robust demographic data, including

ages, socioeconomic and marital status, which would have added to these findings. Future

research should focus on specificity of demographic data (e.g., age range, marital status) in order

to better understand differences and similarities among participants with different backgrounds.

Third, all participants, with the exception of two participants living out-of-state, elected to

participant in a focus group with other parents of YAs with D/MH. While these private

conversations may have resulted in participants sharing more in-depth information about their

experiences as a result of privacy and one-on-one interactions with the interviewer, the

researcher was unable to record other important information relevant to qualitative research such

as body language (Opdenakker, 2006). Further, the dynamics of focus groups and interviews are

notable different, which may have influenced perspectives and experiences participants did

and/or did not share.

Implications for Practice

Despite these limitations, the findings of this study provide several implications. For

example, professionals who conduct diagnostic evaluations should engage in professional

development on how to systematically and meaningfully engage parents in data collection and to

make more accurate diagnoses for YAs with various disabilities including IDD and ASD. This

method of data collection could extend to other family members, including YAs themselves to

gain a more holistic understanding of the YA and provide greater assurance that mental health

evaluations are not colored by disability diagnoses.

Study findings also suggest that school and mental health professionals should work in

collaboration to provide mental health professional development and comprehensive mental

health support for YAs in school systems. Interdisciplinary teams of professionals could develop

and facilitate professional trainings, modified mental health interventions designed for YA with

D/MH (e.g., reducing the pace of instruction, adapting mental health goal-setting strategies;

Fujita et al., in press), and class- or school-wide mental health initiatives to reduce stigma related

to mental health. These trainings should include specific information about supporting young

adults with IDD and ASD, in order to ensure that mental health providers are familiar with the

differing levels of support these young adults may require.

Such programming could destigmatize mental health needs and help students who may

not otherwise receive mental health support. In addition, although participants valued and desired

parent-to-parent connections, as Bazzano et al. (2015) noted, most interventions to support

parents of YAs with disabilities focus on providing respite care and parent support groups,

failing to address the core issue of psychological coping- consistent with findings from this

study. As a result, education professionals can refer parents and other family members (e.g.,

siblings) to family workshops or community gatherings sponsored by family organizations (e.g.,

Parent Training and Information Centers, The Arc, Down Syndrome Association) designed to

help parents of YAs with IDD, ASD, and other disabilities improve their own mental health.

Such organizations may also provide families with additional resources such as respite care.

Further, when necessary, professionals from both school and community sectors could

also support YAs and parents in differing environments by informing YA evaluations or serving

on YA IEP teams in K-12 settings. For example, the inclusion of mental health professionals in

an IEP or transition planning meeting for a YA with IDD would enable the team to gain a richer

understanding of the student's mental health needs and what supports, resources, and activities to

include in the transition plan. Interdisciplinary teams may also collaborate with families to

establish emergency prevention and emergency plans in cases of YA self-harm or aggression. As

necessary, interdisciplinary teams should consist of police officers, individuals from places of

worship, and disability/mental health service organizations (e.g., Parent Training and

Information Centers, National Association for the Dually Diagnosed, Resources to Recover: A

Website for Families) to inform and support YAs and their families.

Finally, the recommendations participants provided for professionals and other families

lay a foundation for policies and procedures to support YAs with D/MH. Mental health strategies

and supports should be systematically incorporated into student transition planning process while

YAs with D/MH are still attending school. This is a time when YAs still live with and have

regular contact with their families, which would allow educators and other professionals to

provide parents information about available services and community supports (e.g., Medicaid

Waivers, parent social groups), as well as provide the entire family the opportunity to learn and

practice implementing strategies while supported by school systems (e.g., living at home and

attending K-12 school).

Implications for Future Research

Research demonstrates the importance of family support influencing the outcomes of

YAs with disabilities (Boehm et al., 2015; Katz et al., 2015; Lindstrom et al., 2011). As a result,

future research should expand upon the findings of this study to explore the experiences and

perceptions of larger numbers of more diverse participants, including entire family units and

YAs themselves. Providing YAs with IDD, ASD and other disabilities and their family members

the opportunity to share their experiences is a critical step in breaking the stigma of D/MH.

Future research should also more deeply investigate parent coping strategies, including

developing the ability to control their own mental health needs to reduce a negative impact on

YA mental health. As Figure 1 displays, future research is needed to investigate ways to reduce

the support demands parents provide YAs with D/MH and create more balanced levels family

interdependence to reduce the parent-YA behavior loop participants reported as problematic. In addition, there exists a need for research-based mental health interventions designed for YA with D/MH that can be implemented in home, school, or community settings by educators, family members, or others who do not have clinical licensure to ensure access to mental health interventions to individuals with varying accesses to formalized mental health services. Future research should also investigate the effectiveness of mental health interventions for YA with D/MH on parent well-being.

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Figure 1

Figure 1

Cycle of Influence of Parent Mental Health (MH) on Young Adult (YA) Behavior
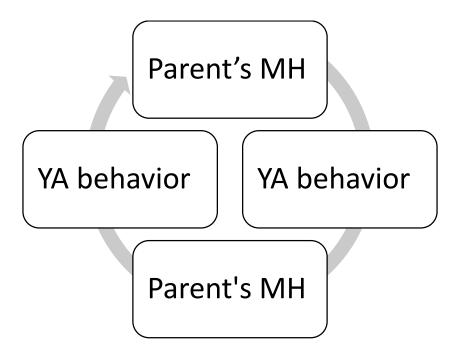
Table 1

Table 1

Participant Demographic Information

Pseudonym	Gender	Age	Race/Ethnicity	Number of Family Members with Disabilities	Age of Family Member with Disability	Focus Group (FG) or Individual Interview (II)	Primary Disability of Family Member	Mental Health Disorder
Angela	Female	56+	White/Caucasian	1	27 years	FG	Intellectual Disability	No formal diagnosis
David	Male	41-45	Black/African American	2	1. 27 years 2. 17 years	FG	1. Emotional Disability 2. Learning Disability	Bipolar schizoaffective disorder
Lola	Female	56+	White/Caucasian	1	(deceased at 25 years)	FG	Intellectual Disability and Attention Deficit Hyperactivity Disorder	Bipolar disorder
Cassie	Female	46-50	White/Caucasian	3	1. 21 years 2. 20 years 3. 15 years	FG	1. Attention Deficit Hyperactivity Disorder 2. Attention Deficit Hyperactivity Disorder (Inattentive) 3. Intellectual Disability (FASD)	Not disclosed
Colleen	Female	46-50	White/Caucasian	1	16 years	II	Autism Spectrum Disorder	1. Schizophrenia 2. Generalized Anxiety Disorder 3. Post-Traumatic Stress Disorder
Marci	Female	41-45	White/Caucasian	2	28 years	FG	Multiple Disabilities	Bipolar disorder
Margaret	Female	56+	White/Caucasian	2	11 years	II	Autism Spectrum Disorder	Bipolar disorder