

PERCEPTIONS OF HEALTH AND HEALTHCARE OF PEOPLE WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES IN MEDICAID MANAGED CARE

Abstract

This study examined perceptions of health and healthcare of people with intellectual and developmental disabilities (IDD) receiving Medicaid Managed Care. Exploratory, semi-structured interviews were conducted with 23 participants. Findings indicate that participants generally expressed being in good health, and defined good health as: (a) absence of pain, disease, and symptoms, (b) adherence to or not requiring treatment, (c) physical self-care, (d) mental or spiritual self-care, and (e) ability to perform the activities one wants to do. Participants conceptualized healthcare as: (a) ensuring needs are met through access to services, (b) obtaining quality services, (c) navigating the healthcare system successfully, and (d) receiving humanizing healthcare. This study has implications for improving healthcare and communications between people with IDD and healthcare providers.

Keywords: health, healthcare, inclusion in research, intellectual disability, developmental disability, Medicaid, managed care

Historically, people with intellectual and developmental disabilities (IDD) have not been included as research participants, as researchers have relied on data from their family members, caregivers, or other informants instead. However, increased recognition of the social model of disability, which defines disability as a social construction and asserts that people with impairments are disabled by society through environmental and attitudinal barriers, has changed how people with IDD are included in research (Tregaskis, 2002). As Jurkowski (2008) noted, “The conception of the social model of disability enabled people with disabilities to place the responsibility for their limitations and barriers to inclusion in research on society and academia...It enabled them to challenge oppressive research methods and policies that do not include their perspectives or experiences” (p. 1). Thus, researchers are increasingly recognizing the need to include people with IDD in research and learn more about their personal experiences and perspectives. Accordingly, the International Association for the Scientific Study of Intellectual Disabilities (IASSID) “asserts that people with intellectual disabilities should not be excluded (discriminated against) as potential participants in...research and every effort should be made to include their perspectives, priorities, and needs in...research activities” (Dalton & McWilly, 2004, p. 59).

Perspectives of People with IDD on Health and Healthcare

One of the key areas in which there is a dearth of information from the perspectives of people with IDD is health and healthcare. Research demonstrates that people with IDD experience numerous disability-related health and healthcare service disparities (Brown & Gill, 2009; Horwitz, Kerker, Owens, & Zigler, 2000; Parish, Moss, & Richman, 2008; Parish & Saville, 2006; Rimmer & Braddock, 2002), many of which result from factors such as inadequate education, access barriers, prejudice and discrimination, and health professionals’ inadequate

training to meet the needs of people with IDD (Brown & Gill, 2009). Nonetheless, the majority of research on the health of people with IDD has primarily relied on information from medical providers, agency staff, and family members, and so little is known about people with IDD's perceptions of their health or healthcare (Brown & Gill, 2009; Parish et al., 2008). The Office of the Surgeon General and Office on Disability in the United States (2005) have called for the inclusion of people with IDD in research on health, healthcare, and long-term services and supports, as have numerous scholars (Krahn & Drum, 2007; [withheld for review]; Marks & Heller, 2003).

The few existing studies that include the perceptions of people with IDD regarding health and healthcare indicates that, generally, people with IDD report that their health is good (Brown & Gill, 2009; LeRoy, Walsh, Kulik, & Rooney, 2004). This finding is consistent with the disability paradox, which observes that many people with disabilities report a good or excellent quality of life, even when external observers assume their quality of life is poor (Albrecht & Devlieger, 1999). These studies also reported that participants had mixed experiences in regards to accessing appropriate healthcare services (Brown & Gill, 2009; LeRoy et al., 2004; Parish et al., 2008).

LeRoy, Walsh, Kulik, & Rooney (2004) used extensive interviews to understand the life experiences of older women with IDD in the United States of America and Ireland. The exploratory study examined health and well-being, as well as personal and economic safety nets and social roles. The women reported that their health was good, although it often limited their ability to engage in activities. Most of the participants had been examined by a doctor within three months of being interviewed, and had received routine preventative health screenings. However, less than one-third of the participants had gone to a dentist within the previous year.

Parish, Moss, and Richman (2008) conducted focus groups with individuals with IDD to better understand their perceptions of their health status, health promotion behaviors, and health care services they received. Participants reported being in good health. While all of the participants had health insurance, many participants reported issues with receiving dental services, reproductive healthcare, and age-specific cancer screening. Participants with family members who served as advocates often had improved access to healthcare services.

Brown and Gill (2009) also conducted focus groups, but centered on women with IDD and their perceptions of health, body awareness, aging, life satisfaction, health behaviors, healthcare experiences, and disability. Generally, participants in their study identified as being in good health, and reported that they had undergone general and reproductive health screenings, such as breast and cervical cancer screenings. Yet, participants also reported healthcare barriers, including difficulty communicating with health providers, a lack of education about health issues, and fear and anxiety around a variety of examinations and screenings.

People with IDD in Medicaid Managed Care

While these studies contained self-reported data from people with IDD regarding their health and healthcare, they were conducted prior to the broad roll out of managed care for people with IDD across the nation. Less is known about the specific experiences of people with IDD enrolled in Medicaid Managed Care (MMC). MMC is a growing trend, with 39 states currently contracting with approximately 265 managed care organizations (MCOs) to provide care to Medicaid beneficiaries overall (Kaiser Family Foundation, 2014). According to the U.S. Center of Medicaid and CHIP Services (2015):

Managed care is a health care delivery stem organized to manage cost, utilization, and quality. Medicaid managed care provides for the delivery of Medicaid health benefits

and additional services through contracted arrangements between state Medicaid agencies and managed care organizations (MCOs) that accept a set per member month (capitation) payment for these services. By contracting with various types of MCOs to deliver Medicaid program health care services to their beneficiaries, states can reduce Medicaid program costs and better manage utilization of health services.

MMC healthcare services have traditionally been provided on a fee-for-service (FFS) basis with any provider who accepted Medicaid; under MMC, Medicaid enrollees have to find providers within a managed care network. This can be problematic for people whose doctors have not contracted with a MCO, forcing people to find new providers, which can affect their experiences with and perceptions of healthcare.

Given that increasing numbers of people with IDD are being transitioned to MMC, it is imperative that people with IDD be included in evaluations of the impact of MMC. As Hall, Kurth, Chapman, and Shireman (2015) observed, in the context of MMC, “Little is known about the experiences of people with disabilities” (p. 130), and this dearth of knowledge is particularly true for people with IDD. The purpose of this study is to explore the perspectives of people with IDD enrolled in MMC and better understand how they perceive their personal health and their experiences with healthcare within MMC. The research questions this study addresses are: (1) What does good health mean to people with IDD? (2) How do people with IDD conceptualize high quality healthcare within MMC?

Methods

This study is part of a larger evaluation of MMC in a Midwestern state. The goal of the data presented in this article was to understand the perspectives and experiences of people with IDD in MMC. The larger study, including the present study, had a consumer advisory board of

people with disabilities, their families, and providers that met monthly to guide the conceptualization, survey/interview development, implementation, and interpretation of the study.

Sampling and Participants

A total of 23 participants volunteered to participate in the study, all with various levels of IDD. Some participants also had other disabilities, such as mental health impairments or physical disabilities. All participants were verbal and spoke English. The participants, their pseudonyms, and their demographics are listed in Table 1 and a summary of the sample is included in Table 2. Fourteen (60.9%) identified as female, and nine (39.1%) identified as male. Fourteen (60.9%) identified as Black or African-American, two (8.7%) identified as Latino or Hispanic, four (17.4%) identified as White or Caucasian, one (4.3%) identified as other, and two (8.7%) declined to answer. Two (8.7%) were married or living with a partner, eight (34.8%) were divorced or separated, two (8.7%) were widowed, ten (43.5%) were single and never married, and 1 (4.3%) declined to answer. Participants' ages ranged from 24 to 63 years old, with an average age of 49 years old.

[Insert Tables 1 and 2]

The participants in the study were recruited in conjunction with a related study that randomly surveyed people with disabilities enrolled in MMC in a Midwestern city and surrounding counties, or families or informants of people who had IDD for people who were not their own guardians. The survey included space for the informant to indicate whether the Medicaid enrollee with IDD was interested in directly participating in the research and the best way to contact that person. The person who submitted each survey that indicated that a person with IDD wanted to participate directly was contacted and the telephone interview protocol was

explained. After informed consent was received, the research team scheduled a telephone interview with the person with IDD.

To ensure the protection of participants, this study was approved by the university Institutional Review Board (IRB). Furthermore, all participants and, if applicable, their guardians, consented to participate in the study. Some guardians requested to listen to the phone interview as it was occurring, which was permitted. Participants were informed they did not have to answer a question if they preferred not to, and they could withdraw from the study at any time.

Data Collection

An exploratory, semi-structured telephone interview was conducted with each participant. The interview guide was based on a survey instrument being used with other people with disabilities or informants, and included questions on their overall health status, satisfaction with healthcare, and experiences with primary care providers, specialists, and care coordinators. Probing questions were used to encourage participants to further explain their answers. The interviews lasted between 20 and 40 minutes. The interviewer took detailed notes to capture participants' experiences and perspectives.

Data Analysis

Data were analyzed using a general, inductive qualitative approach. According to Thomas (2006), "The primary purpose of the inductive approach is to allow research findings to emerge from the frequent, dominant, or significant themes inherent in the raw data, without the restraints imposed by structured methodologies" (p. 238). Following Thomas' (2006) suggestions, the researchers used the following analytic procedure: (1) raw data files were configured to a single document with common formatting (in terms of font, margins, etc.), (2)

two members of the research team read the raw data in detail several times and independently coded the data, developing codes as needed, (3) the two members of the research team then met and shared codes, (4) codes were reduced to account for overlap and redundancy, and (5) the research team members used the remaining codes to create categories and themes relevant to the research objectives.

Results

What Are People with IDD's Perceptions of Health?

Participants generally thought they were in good health. Five themes emerged on how they defined good health: (a) absence of pain, disease, and symptoms, (b) adherence to or not requiring treatment, (c) physical self-care, (d) mental or spiritual self-care, and (e) ability to perform the activities one wants to do.

Absence of pain, disease, and symptoms. Many participants defined good health by the absence of pain, disease, or symptoms. Several participants focused on a lack of pain as an indicator of health, noting that good health was marked by:

“No aches and pains.” – Carl

“I am not in pain or anything.” – Lorraine

“No pain, feeling good.” – Celia

Participants also focused on the absence of disease as a sign of good health. Julia said that good health meant, “I don’t have any diseases or anything like that.” Similarly, Jamie defined good health as “nothing wrong.” For those with chronic diseases or impairments, good health was equated with an absence of symptoms. For instance, Evan defined good health as “No seizures,” and Lorraine said, “No high blood pressure.” Thus, although participants were influenced by

their individual situations (e.g., temporary illness versus chronic illness, issues with pain), they generally equated good health with the absence of pain, disease, or symptoms.

Adherence to or not requiring treatment. Some participants characterized good health as adhering to recommended treatment. For instance, Micah said good health meant, “I take my pills every day.” For other participants, good health meant seeking needed services; for instance, Ciera mentioned “[getting] check-ups” regularly. Marianne said, “I had my leg worked on, the past few years I was wobbly...and I couldn’t get...far without [the surgery],” stressing the importance of that treatment. Conversely, for other participants, good health meant not needing medical interventions at all. For instance, participants said a part of good health was:

“No pills being taken.” – Laura

“Not having to take a lot of meds.” – Jackie

“No surgeries.” - Evan

Overall, this theme showed that participants felt that good health meant not having medical interventions; however, if interventions were needed, participants recognized the need to adhere to the prescribed treatment.

Physical self-care. Another way of defining health related to physical self-care, such as healthy eating and exercise. For instance, several participants discussed the importance of nutrition. Vincent noted that a part of good health was “healthy eating.” Micah similarly said that good health meant, “I eat every day.” Ciera noted that she believed she was somewhat healthy due to her nutrition, stating, “I eat a lot of vegetables.” A few participants also discussed exercising. For instance, Matthew spoke about going to his local YMCA regularly, and Micah talked about playing sports. Evan discussed the importance of balanced exercise, stating, “I

exercise for a little bit, but not too much.” For these participants, an essential aspect of good health was taking care of their bodies in various ways.

Mental or spiritual self-care. A related theme about the meaning of health was mental or spiritual self-care, which involved engaging in activities that enhanced one’s mental or spiritual health. Several participants viewed good health as a state of mind. They identified health as:

“Feeling well.” – Ronnie

“Feeling good.” – Ciera

“[Being] happy.” – Vincent

For spiritual participants, religion played an important role in self-care. For instance, Henrietta discussed the importance of going to church, which helped her to feel calm and peaceful. Similarly, Micah said he felt happy by “praying to God.” Religion also played a role in state of mind, as religious participants reported feeling blessed or fortunate. For instance, Jamie said that, in spite of various health conditions, “[I’m] blessed as far as health.” Similarly, Henrietta took comfort in believing “it’s all in God’s hands.” Generally, these participants did not view health as solely defined by one’s physical state, but rather recognized that good health has a mental and spiritual components.

Ability to perform the activities one wants to do. Lastly, several participants defined good health as the ability to engage in activities, such as walking, communicating, and socializing. For instance, Gayle said, “Being healthy [means] the world to me. [It means I can] walk, talk, and go visit [people].” Jackie said good health was, “Being able to get around and about.” Matthew said good health meant he “[could] do a lot of things.” Jackie, who has chronic obstructive pulmonary disease said her health as fluctuated based on how her symptoms

influenced her ability to be active: “I have good days and I have bad days. [My health is] not good or bad cause I got days that are really good and I am active and then days that it’s limited what I can do because I can’t breathe.” Thus, some participants evaluated their health based on their ability to continue to engage in basic activities (e.g., walking and talking) as well as desired activities (e.g., socializing, visiting people).

Overall, participants’ perceptions of their health were generally positive. Participants defined good health through a number of factors. Some conceptions of good health focused on the lack of bodily experiences and medical care, such as the absence of pain, disease, and symptoms, or following treatment or not needing treatment. Other perceptions of good health included having a positive or content state of mind, engaging in self-care, and having the ability to do the activities one wants to do, such as getting from place to place or socializing.

What are People with IDD’s Perceptions of Healthcare within MMC?

Four themes emerged in regards to how participants conceptualized high quality healthcare within MMC: (a) ensuring needs are met through access to services, (b) obtaining quality services, (c) navigating the healthcare system successfully, and (d) receiving humanizing medical care.

Ensuring needs are met through access to services. Participants discussed having their needs met through services, and described two different levels of service provision: access and quality. Access involved being able to secure or use the services one needed. Lorraine said healthcare meant, “I can get the services that are needed to me.” Marianne said healthcare involved “[getting] all medical stuff done...not like [the MCO is] in the way.” Ronnie defined healthcare as, “Always [getting] meds when you need them, referrals, always [getting] in to doctor.”

Another part of access was the availability and timeliness of services. Some participants discussed that their doctor's availability mattered in their care. For instance, Monica said she wanted to be able to "go [to a doctor] without calling," and Ronnie said he was happy when it "won't be a problem going to the doctor, [because they are] available." Lynda classified her healthcare as good because her providers were "right on time for everything." Conversely, Gwen felt ambivalent toward her healthcare because she had to "wait a long time to see doctor, sometimes [the doctor is] not there when I schedule an appointment."

Additionally, for some participants, logistics could either support or impede access. For instance, some participants had no issues with transportation, either because family or friends provided it or their MCO had paid for it. Lorraine noted, "Scheduled vehicles...have taken me to and from my doctor's appointments." However, other participants did not receive assistance with transportation from their MCO, even though they needed it. Daniel said, "Paperwork was filed for the transportation but I haven't received it yet," and Lynda noted, "I did not get it, but need it." Overall, accessing services involved being able to use the services one needed and incorporated a broad range of factors, including ensuring their MCO approved and paid for the services they needed, securing primary care physician referrals, receiving timely services, and having logistical support.

Obtaining quality services. Once services were accessed, participants discussed another level of service provision: quality. Quality services, which included primary care providers, specialists, and hospital services, were defined largely by the knowledge, skills, and experience of providers. In general, participants viewed their doctors as very knowledgeable and professional. Julia said, "[My doctor] is very knowledgeable with the questions I ask him." Daniel said his doctor "gives me the right answer, right solutions." Carl described his doctor as

“outstanding with personality and professionalism.” Susie felt very positive about the services she received due to their comprehensiveness, noting that she was happy with her healthcare because she saw a “thorough primary care provider and gynecologist.”

Several participants also highlighted when their doctors were knowledgeable about their specific impairments. Gayle noted that her doctor “explained things to me about diabetes.” Likewise, Lorraine said, “I have a very good PCP. He’s been my doctor for the past 10 years. He deals with people who have depression, so it’s easy for me to talk to him.” Monica noted that doctor is “very knowledgeable [and] knows exactly what types of treatment to give me when I had a mental breakdown.”

Participants also emphasized the importance of doctors using accessible and understandable communication methods. For instance, Celia said, “[My doctors] take care of me good, I understand when they talk to me.” Similarly, Julia felt her healthcare was good “because the doctor answered all the questions that I needed to be answered and in a way I could understand.” Julia later added, “[My doctor] breaks it down. He makes it easy to understand.”

Yet another part of receiving quality services was having providers and care coordinators connect participants to other resources, such as specialists or community organizations. Lorraine viewed her primary care provider as knowledgeable because “he made the referrals to the pain doctor I have and the spine doctor, so he is helpful in that.” Monica shared that her care coordinator “helps with mental health, contacts nutritionist program, she will contact weight loss and [personal assistance] program for me.” Generally, quality services involved the knowledge, skill, and experience of providers (including knowledge of specific impairments or illnesses), and having providers and care coordinators who were able to communicate effectively with participants and connect participants to additional resources.

Overall, participants defined excellent healthcare using two levels of service provision: access and quality. These two levels are presented as two distinct themes because one does not necessarily guarantee the other. However, ideally the two are linked in a system in which participants receive access to high quality services.

Navigating the healthcare system successfully. A central part of successfully navigating the healthcare system was working with the MCO to ensure needed services were covered. For example, Henrietta identified that “working with the insurance company” was a major part of healthcare. Participants discussed the coverage of medical services, such as treatments and prescriptions, as well as long-term services and supports, such as personal assistants. Many people reported being happy with the coverage their insurance was providing. For instance, participants shared:

“[MCO] takes care of my business, takes care of all my services.” – Luis

“[MCO] covers me. I don’t have to pay for It.” – Matthew

“Now [I don’t] pay for prescriptions.” – Monica

“I don’t pay for copays or meds.” – Ronnie

Delays in having services covered resulted in some participants being less happy with the MCO. Daniel shared, “I need a personal assistant and [it] took a long time. [I] Had to have family members help and they didn’t always know what to do.” Similarly, Henrietta noted that she was feeling blue because she felt she was “being treated like a child by [her MCO]” in regards to her access to Certified Nursing Assistant services.

Another important part of navigating the healthcare system was understanding and utilizing care coordination. Some participants did not know if they had a care coordinator. Ronnie said, “I’m not sure if I have a care coordinator, only on the plan for one year though. I

expect this person to be contacting me soon.” Gayle said, “I don’t know [if I have a care coordinator], probably not yet.”

For participants who did have care coordinators, they reported a mix of negative and positive experiences. Some participants were frustrated with their care coordination experience. Many of their concerns were related to a lack of communication or miscommunication. Celia said, “It’s going on a year since the care coordinator talked to me.” Donna said, “I just met [my care coordinator] a few weeks ago, just showed up unannounced.” Henrietta felt her care coordinator did not take into account her wishes for her own care. She said, “She’s not too concerned about the medication, she wants to give me the meds that are covered and does not listen to me.”

However, other participants noted that their care coordinator was supportive and helpful. Matthew felt his care coordinator did not take into account his wishes and so he switched to a different care coordinator. He reported his new care coordinator “call[s] once a month, [helps] get medical equipment, get pharmacy stuff, get [MCO] to pay for pharmacy.” Jackie recalled, “She tried finding me a dermatologist, she went out of her way to send me places that she thought might take the insurance, unfortunately out here most dermatologists do not take [insurance], but she did everything possible to help me find somebody. Same with the eye doctor and dentist, she went out of her way to listen and to find me someplace where the insurance covered it.” Laura said that her care coordinator “notices my squinting eyes and [asked about] seeing an eye doctor. She said she could schedule an appointment.” Matthew said his care coordinator “help[s] me get my medical equipment, schedule appointments, [and] asks if I am fine.”

Generally, participants perceived navigating the healthcare system as a central part of healthcare, and defined this primarily through working with the MCOs to ensure needed services and prescriptions were covered. Most participants were pleased with the coverage they received from their MCO, though some people were frustrated by delays in having needed services approved or covered. Another aspect of navigating the healthcare system was understanding and utilizing care coordinators. Some participants expressed uncertainty or confusion about whether they had been assigned a care coordinator or not. For those that did have care coordinators, some reported positive experiences characterized by strong communication, support, empathy, and going above and beyond. Others reported mixed or negative experiences, which were often due to a perceived lack of communication or miscommunications between the care coordinator and participant.

Receiving humanizing medical care. Receiving humanizing medical care consisted of being treated as an individual and having a good relationship with medical providers. Many participants emphasized the importance of receiving personalized or individualized care. Jackie discussed disliking her primary physician because he did not treat her as an individual and provided overly-routinized care: “He just keeps the same prescriptions...and just listens to my heart and lungs. He just sees you for two minutes, fills prescriptions, and you’re off.” Conversely, Marianne felt her doctor listened to her and respected her individual wishes. She defined healthcare as medical care that helps her “to feel like a person again.”

Relatedly, participants also indicated that having a positive relationship with providers was a significant part of receiving humanizing medical care. Participants discussed the importance of doctors listening, demonstrating care/concern, and exhibiting patience. Donna stated, “The doctors have been listening and [they] find the better solution.” Vincent said, “[My

doctors] are there and care for me.” Henrietta observed, “[My doctor] is concerned about [my] situation, and tries to help me the best that she can, gives me excellent help.” While the majority of participants reported being happy with their primary care providers and specialists, having a poor relationship with a doctor was detrimental to Jackie. She shared:

“I am unhappy with my doctor. I am so unhappy with him, if he’s the only one there, I won’t go. I will book it only when his understudy is there...I will miss my appointment because he’s the only one there...I know that’s bad for my health but...he pushes my buttons and is very rude and makes me feel stupid. He has a tendency of making you feel beneath him. He’s a doctor and you’re just a patient and you don’t know anything. I know my body and I know and I know if something is wrong with me – I’ve been in my own body for 50 years. He thinks he’s better and smarter than I am and we bump heads, we clash.”

Fortunately Jackie was satisfied with the other doctors in her primary care provider’s office, noting, “[The other] doctors, I love. They have my wellbeing at heart...they treat you like a human being.”

Hence, participants viewed receiving humanizing medical care, which was predominately characterized by positive, supportive, and caring relationships with providers, as an important aspect of their healthcare. Although the vast majority of participants reported positive relationships with primary care providers, specialists, and other providers, one participant did have a negative relationship with a provider, which was detrimental to her ability to obtain quality healthcare. In general, participants expressed the desire for providers to listen to them, respect them as individuals and human beings, and address their medical concerns.

Discussion and Implications

Discussion

This research builds on a limited base of existing scholarship that explores adults with IDD's perceptions of health and healthcare. Furthermore, this research specifically focuses on people with IDD who are enrolled in MMC, which is a growing trend in the United States. It is essential that the experiences of people with disabilities, especially IDD, within MMC are better understood.

Overall, participants identified as being in good health, which supports previous research findings regarding people with IDD's perceptions of their health (Brown & Gill, 2009; LeRoy et al., 2004). Participants' conceptualizations of good health were defined by a number of physical, mental, and spiritual factors, suggesting that participants viewed good health in diverse ways. Some participants discussed a variety of factors in a single interview, implying that they recognize that good health was multifaceted.

One notable finding that was not readily apparent in existing literature on people with IDD's perceptions of their health was the importance of spirituality and religion in participant's conceptualizations of good health. Participating in religious or spiritual activities, such as going to church or praying, was a prominent form of self-care for numerous participants. Additionally, believing in a higher power also served as source of comfort for some people, regardless of their medical situation. Additional research about the influence of spirituality and religion on people with IDD's views of their health is warranted.

Participants were also generally pleased with the access to services and the quality of services they were receiving. Many reported they were satisfied with the coverage provided by their MCO, particularly in regards to prescription medications and copays. Some participants

had unmet needs, notably for personal assistant services, transportation, home health care, and dental services. Previous research has reported that people with IDD also experience limited access to dental care (Anderson et al., 2013; Parish et al., 2008). Despite these unmet needs, most participants reported access to preventative care and routine health screenings, which is consistent with the findings of Brown and Gill (2009) and LeRoy et al. (2004), but inconsistent with the findings of Parish et al. (2008). One possible reason for this discrepancy is that, as Ouellette-Kuntz, Cobigo, Balogh, Wilton, & Lunsby (2015) observed, access to health screenings for people with IDD is influenced by factors such as education, income, age, and geographical location. These factors may have differently affected the participants in these studies. Furthermore, while the majority of participants in the Parish et al. (2008) study reported being on Medicaid or dually enrolled in Medicaid and Medicare, participants in Brown and Gill's (2009) study only shared that participants had access to health insurance, but did not share if it was public or private, which may have also influenced access.

One of the most salient facilitators of positive perceptions of healthcare was a positive relationship with providers, whereas a negative relationship with providers proved to be a significant barrier for some participants. One participant in particular noted that she would skip or hold off on doctor's appointments if she had to see her primary care provider, rather than his understudies. She made it clear that one of the reasons she had a poor relationship with this doctor was because he treated her like she was unintelligent, and did not value her opinion or knowledge about her body. This is particularly important since Brown and Gill (2009) found that their participants reported that difficulty communicating with healthcare providers was a major barrier to healthcare. Conversely, many participants who had positive relationships with their providers noted that they were treated with respect and care. Several participants also

emphasized how important it was to them that their doctor answered all their questions with patience and communicated in accessible, easy to understand ways.

Limitations

Although it is not the intent of qualitative research to be generalizable to the larger population, it is still important to note that the findings of this study are based on 23 adults with IDD who are not representative of the larger population of people with IDD. Specifically, since all participants needed to be verbal to participate in the interviews, the sample likely excludes people with severe impairments. Additionally, although the sample was racially diverse, with predominantly Black participants and White participants, only two participants identified as Latino/a. All participants spoke English, as the research team lacked the resources to conduct interviews in Spanish. Furthermore, no Asian-American, Native American, or Pacific Islander persons were interviewed. Future research should strive to better understand the unique experiences of these specific populations. Lastly, this study was limited to a focus on the perceptions of people with IDD regarding their health and healthcare. More research is needed that also compares the perceptions of people with IDD to actual Medicaid claims data to gain a better understanding of their overall health status and the services that they need and receive.

Implications

This study has important implications for health care providers and MCOs within MMC. One of the key findings of this study is that people with IDD highlighted the importance of being treated with respect and dignity both their providers and their MCOs. They also emphasized the value of relationships with their providers. Historically, people with IDD have been disempowered, dehumanized, and not identified as full citizens (Armstrong, 2002; Dybwad & Bersani, 1996; Friedman, Arnold, Owen, & Sandman, 2014). Consequently, this long history of

oppression may make relationship-building and humanizing treatment within medical care particularly important for this population.

Relatedly, many participants identified the significance of accessibility in regards to medical care. Specifically, it was important for participants to have primary care physicians and other providers who were able to communicate clearly and in common, everyday language to ensure participants understood their diagnoses and subsequent treatment. Physical and environmental barriers are often thought of regarding accessibility, while less attention is given to how providers can communicate with their patients with IDD in inclusive ways.

Another important finding is that some participants expressed confusion regarding care coordination. Many were unsure if they had been assigned a care coordinator, or did not know what their care coordinator's job responsibilities entailed. This finding suggests that MCOs need to ensure that their members with IDD are receiving accessible information on care coordination, which would support them in more successfully navigating the healthcare system within MMC.

As assessments of consumer satisfaction with MMC health care are mandated, it is essential that these assessments include not only the perspectives of families and other informants, but also the perspectives of people with IDD. Hence, other modes of gathering data other than written surveys and cognitively inaccessible interviews need to be used. Future research could also include other modalities of gathering data such as tablet and computer applications that are accessible to people with IDD.

Conclusion

As many states transition to Medicaid Managed Care it is important to include the voices of people with IDD to better understand what good health means to them and how they perceive the healthcare they receive. States, MCOs, and other stakeholders need data to help ensure that

services are meeting the needs of people with IDD. Such work is especially important as MCOs shift from only providing medical care to more integrated care that also manages long-term services and supports, areas of particular importance to people with IDD and their families.

In particular, this study's findings related to healthcare emphasize the importance of MCO networks. Much of the discussion about good healthcare referred to the relationship with providers, especially humanizing treatment. It is important for providers to listen to the wishes of people with IDD and treat them with respect. MCOs also need to ensure that their network providers are sufficiently available to members who need care. Related to this, care coordinators need to be able to better communicate with people with IDD to help them navigate the healthcare system. People with IDD who reported positively about their care coordinator also reported more positively about healthcare in general.

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