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Selective service: Experiences of speech-language pathologists serving underrepresented populations

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Abstract

Members of underserved populations, particularly those of low socioeconomic standing, are less likely to receive speech-language pathology services. Through a series of indepth interviews, this study observes the experiences of speech-language pathologists working with underserved populations in order to understand how they help such populations. The subjects include at least one speech-language pathologist from each of the following settings: school, private practice, hospital, and skilled nursing facility. Results of this study yield common themes in working with members of underserved populations, as well as implications for improving the accessibility of speech-language pathology services.

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SELECTIVE SERVICE: EXPERIENCES OF SPEECH-LANGUAGE PATHOLOGISTS
SERVING UNDERREPRESENTED POPULATIONS

By

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Abstract

Members of underserved populations, particularly those of low socioeconomic standing, are less likely to receive speech-language pathology services. Through a series of in-depth interviews, this study observes the experiences of speech-language pathologists working with underserved populations in order to understand how they help such populations. The subjects include at least one speech-language pathologist from each of the following settings: school, private practice, hospital, and skilled nursing facility. Results of this study yield common themes in working with members of underserved populations, as well as implications for improving the accessibility of speech-language pathology services.

Introduction

Many people of various ages and backgrounds rely on speech-language pathology services to improve their communication skills and overall quality of life. For example: 7.5 million people in the United States have voice complications, 6-8 million have a language impairment, and 8-9 percent of children have a speech sound disorder (NIDCD, 2016). These services are generally provided through one's insurance in the United States. According to a 2016 study conducted by Mirza and Kim, having necessary rehabilitative services such as speech therapy covered by one's insurance increases one's opportunities for social participation. Despite the necessity of such services, the same study discussed the reality for significant percentages of children with disabilities: a lack of or uncertainty of coverage for these services, even with insurance. Another study looked at therapy needs for children and found that one in five children are not able to receive the services they need, with the odds being higher for children of color and from lower-income households (McManus et al., 2016). Barriers such as insurance and socioeconomic status obstruct many individuals in the United States from utilizing the services they need or decrease the quality of service that they may receive.

The purpose of this thesis is to find out more information about how speech-language pathologists help underserved populations such as those that are uninsured or with a low socioeconomic standing. The particular question being asked is: What are the experiences and perceptions of speech-language pathologists across different settings working with members of underserved populations? The answers discussed in this thesis provide valuable insight for those interested in working with such populations, as well as

problems and solutions regarding the accessibility of speech-language pathology services for such populations, as stated by experienced, practicing speech-language pathologists.

Literature Review

Importance of Speech-language Pathology/Therapeutic Services

When access to speech-language pathology and therapeutic services is granted, research has consistently demonstrated the resulting benefits. Luyten et al. (2016) studied the effects of providing short-term speech-language pathology services to several cleft lip/palate patients in Uganda, who otherwise did not have access to services. The accelerated model of service successfully resulted in improved speech across all patients, demonstrating the benefit of this model of service for patients deprived of access. Another study examined the effects of short-term speech-language pathology services on individuals with Parkinson's Disease, who are rarely recommended for services, and found significant improvements in speech and voice for those who underwent the services (Simberg et al., 2012). Ullrich et al. (2014) studied the benefits of early speech/language intervention and found that children who received services prior to grade school were overall academically successful in the long-term. Additionally, in a survey regarding speech and other therapy services for children with autism, about 60% of caregivers stated: "their child benefited 'much' or 'very much' from care" (Monz et al., 2019, p. 522).

In addition to the direct benefits of access to speech-language pathology and therapeutic services, studies have demonstrated indirect benefits of being able to access such services. According to Mirza and Kim, children who had insurance coverage for

speech-language pathology/rehabilitative services were nearly twice as likely to be socially involved (2016). For parents of children with autism, it was found that when having increased access to related services such as speech/language therapy and behavior therapy, there was a decrease in parent stress and overall better outcomes for families (Young et al., 2009).

Barriers to Access

While research has demonstrated the benefit and necessity of speech-language pathology and therapeutic services, utilization of such services is not always there. One study analyzing the use of services by children with autism in the United States found that 96% utilized at least one type of service, with the majority of them at least utilizing speech/language therapy or occupational therapy services (Monz et al., 2019). However, according to Benedict, “Among children with functional limitations, an estimated 15 percent have an unmet need for therapeutic services and 11 percent have an unmet need for supportive services” (2006, p. 111). Benedict’s study regarding the utilization of therapy services found a number of factors contributing to the ability of individuals to utilize services, including: family income, education, and insurance type. Similarly, McManus et al. (2016) discovered that nearly 20% of children requiring therapy are not receiving the therapeutic services that they need. A number of other studies have identified various barriers to access of speech-language pathology and therapeutic services.

Socioeconomic Status

Studies have demonstrated the effect of socioeconomic status (SES) on access to services in numerous ways. One way is through deferring care; Donley et al. (2018)

found that reception of health services was delayed at significantly higher rates for individuals and families with financial difficulty and lower socioeconomic status.

Ghandour et al., (2015) discovered that socioeconomic status additionally affects the ability of families to cover the cost of services or have insurance coverage for services, thus hindering access. Children who came from families with an income that was less than 4 times the federal poverty level were more likely to lack necessary therapeutic services (Ghandour et al., 2015; McManus et al., 2016). Furthermore, Benedict (2006) found that children from families with an income below the federal poverty level had a 40% lower chance of receiving therapy services. Another factor of SES that was found to affect access is education level; having a person in the family with a post-high school education made families more likely to pinpoint a need for therapeutic services (Benedict 2006). Factors that arose when examining effects of income level in children with cochlear implants included: reduced presence for follow-up appointments and higher development of complications. These factors resulted in worse speech/language outcomes for lower-income children with cochlear implants (Chang et al., 2010).

Insurance

In general, having insurance coverage is found to increase access to therapeutic services. Having insurance decreased the chances of health care services being deferred by nearly 70% (Donley et al., 2018). When it came to utilizing therapeutic services outside of school, children with public insurance had over twice as much of a probability to do so than those without any insurance (Benedict 2006). McManus et al. (2016) additionally determined that the likelihood of lacking necessary therapy services was doubled for children who had had any experience within the last year of being uninsured

than those who had been unceasingly insured. Another study examined the effects of extending public insurance in certain states to immigrant children from low-income families who otherwise lacked insurance; access to health services was greatly increased for the children in the states who provided them with public insurance than for those in the states that didn't (Saloner et al., 2014).

When it comes to public versus private insurance, however, the studied effects on access to services are varying. On one hand, Donley et al. (2018) found that having health care be deferred was almost twice as common in individuals with public insurance. Uncovered expenses for speech-language pathology services were also much greater for Medicaid children than for privately insured children in a study done within the state of Kentucky (Young et al., 2009). On the other hand, the likelihood of accessing therapy services outside of school were over twice as much for children with public insurance than privately insured children (Benedict, 2006). Wang et al. (2013) also discovered more coverage of speech/language therapy, behavior therapy, and other therapy services for publicly insured children with ASD than privately insured children with ASD. Another contradictory study compared publicly and privately insured children with hearing loss, and found that access was relatively similar for both groups (Smith et al., 2019).

Race/Ethnicity

Decreased access to services for racial/ethnic minorities has been consistently demonstrated. Ghandour et al. (2015) found that inability to cover the cost of therapy services disproportionately affected children who were Hispanic or non-Hispanic. Relating race and ethnicity to SES, about 30% of black children and 30% of Hispanic children with ASD and other special health care needs were considered to be below the

federal poverty level, as opposed to >14% of white children with ASD and other special health care needs that were considered to be below the federal poverty level (La Clair et al., 2019). Accordingly, race/ethnicity were related to a lack of necessary therapy services; for example, non-Hispanic black children were 30% more likely to lack necessary therapy services than non-Hispanic white children (Benedict 2006; McManus et al., 2016). However, when increasing laxness in Medicaid waivers for coverage of therapeutic services, it was found that utilization of necessary therapy services also increased for black children with ASD, in turn decreasing the gap between black children and white children. Although the greater laxness for waivers benefited black children, it did not have any significant effect for Hispanic children, perhaps due to cultural causes (La Clair et al., 2019).

Children with Special Health Care Needs

Children with special health care needs (CSHCN) are often at a disadvantage when it comes to accessing services despite the fact that they are generally more in need of them than children without special health care needs. They have twice as much of a chance of having health care services be postponed than non-CSHCN (Donley et al., 2018). Kuhlthau et al. (2010) determined that the guardians of academically/socially limited children tended to have poorer income and employment rates. Correspondingly, the chances of families with CSHCN having difficulty with medical expenses was twice as much as those without CSHCN. They had higher likelihoods of lacking necessary services and sufficient coverage for services (Miller et al., 2011). CSHCN were also found to lack access to therapy services outside of school based on restrictions in movement and personal attendance (Benedict 2006). Those who specifically had

developmental disabilities experienced thrice the likelihood of lacking necessary therapeutic services compared to those with medical ailments (McManus et al., 2016).

Other

Numerous additional factors were found to impact accessibility of therapeutic services. Geographic location was one factor, with urban areas having far more available speech-language pathology and behavioral therapy services than less urban areas. Urban areas, however, were much more likely to have waiting lists that hindered access to services (Monz et al., 2019). Age was another factor that impacted accessibility; children of older age had a greater likelihood of not being able to have sufficient coverage/funds for therapeutic services (Ghandour et al., 2015). Immigration status and primary language additionally came into play for several studies. Coming from a non-English speaking family, which is the case for nearly half of immigrant households with CSHCN, had a negative correlation to the ability to afford therapeutic services (Ghandour et al., 2015; Javier et al., 2010). Children with special health care needs that lived in immigrant households had a greater likelihood of being deprived of medical visits, insurance coverage, and overall health care services than those in nonimmigrant households. These circumstances were even more dire for those in families with undocumented immigrant status (Javier et al., 2010).

Methodology

Study Design

This study used a qualitative interview approach to obtain in-depth experiences, perspectives, and reflections of speech-language pathologists regarding service of

members of underserved populations across different settings. The field of speech language pathology typically runs across four main settings: schools, hospitals, private practices, and skilled nursing facilities. I planned to recruit a minimum of one speech-language pathologist who has had significant experience with members of underserved populations within each of these general environments, for a total minimum of four participants.

Once I obtained human subject approval from the University Human Subject Review Committee, I emailed letters of recruitment to potential subjects. Selected interviewees received and signed forms of informed consent, primarily for audio recording, prior to interviews taking place. Each interviewee underwent one interview that was loosely guided by a set of questions regarding the interviewee's past educational/professional experiences in speech-language pathology, present position, experiences with members of underserved populations, and reflections of their experiences with respect to members of underserved populations (Seidman, 2013). These interviews lasted roughly one hour in length and were conducted in mutually agreed upon private spaces: either participants' offices or library meeting rooms. Once all of the interviews were completed, they were transcribed and analyzed for common themes.

Participants

The population of interest for this study included speech-language pathologists within the general area of southeast Michigan who met three general requirements: clinically certified by the American Speech-Language-Hearing Association (ASHA), practiced within one of the specified settings, and have had significant experiences with members of underserved populations while practicing. These experiences were

understood to include, for example: people of low socioeconomic status, racial/ethnic minorities, Medicaid/Medicare recipients, and homeless or uninsured individuals.

Convenience sampling was used to accrue the subjects. This method was selected due to the sit-down nature of the qualitative interviews required for the study and limited access to speech-language pathologists across different settings. Participants that were recruited included personal contacts and contacts that were recommended to me by my faculty mentor, professors, and other personal connections within the specified settings. I first reached out to the initial contacts I had for each setting. Depending on whether or not I received responses, I then obtained more contacts from my personal connections to reach out to until I had at least one participant confirmed for every service setting.

The study ended up including a total of five participants. Of the participants, two were personal contacts who I knew prior to the study, and three were referred to me through other personal connections. All of the participants were currently practicing in Michigan. Three of the participants had educational and previous professional experiences outside of Michigan but still in the Midwest region, while the educational and professional experiences of the two other participants were fully within Michigan. The present positions of the participants included: two in private clinics, one in a skilled nursing facility, and two in hospitals. Past and present positions of the participants included: two in private practice, two in a skilled nursing facility, two in schools, and four in hospitals.

To protect the privacy of the participants, selected pseudonyms will be used to refer to them. The first participant that I interviewed was Evelyn. Evelyn has had 10 years of experience working in a low-income school district, as well as 10 years of

working in a private practice. Within her private practice, Evelyn delivered services for one year at an autism clinic and has been delivering in-home therapy services for nine years now. The second participant I interviewed was Louise, who had the most experience of all the participants. Louise worked at a hospital for a couple years, but then transferred to skilled nursing facilities, where she has been for over 20 years. Becca was my third interviewee. She was the newest to the field, with one and a half years of experience in a hospital outpatient setting, and two years now at a private autism clinic. I then interviewed Simone, who was the only black participant. She spent seven years working in two different low-income school districts, six years in a skilled nursing facility, and now works in a pediatric hospital outpatient setting, where she has been for nine years. The last participant I interviewed was Daniel, the only male participant. Daniel worked for one year in a hospital outpatient setting and has now been working for five years in a hospital acute and inpatient setting.

Table 1

Participant Work Experience

	School	Hospital	Skilled Nursing Facility	Private Practice
1-5 years		Becca Louise		Becca Evelyn
6-10 years	Simone Evelyn	Simone Daniel	Simone	
20+ years			Louise	

Findings

After transcription and analysis of the interviews, several trends were highlighted across the varying experiences of the participants. The following recurring themes arose in regards to the accessibility of speech-language pathology services for members of underserved populations: insurance, family dynamics, communication skills of speech-language pathologists, and prevalence of services.

Insurance

In general, participants said that insurance is needed to access services. The only exceptions to this are services provided through schools and certain hospital settings. For acute hospital care, Daniel claimed, “If someone comes into the hospital, [it] as a public institution can't turn anyone away.” However, when transferring to inpatient care, he said, “If the person is insured at all, that’s one thing that probably affects whether or not they come to inpatient rehab in the first place.” He clarified:

Now, that doesn't mean that it’s the only thing that goes into it. I mean I can think of several people who have come to inpatient rehab who haven’t been insured, and we certainly try not to make that be the only thing in terms of if the person needs it, they try to take them.

Having insurance is only one part of it, however; struggles stemming from insurance policies and insurance companies as a whole resonated with each participant interviewed. To put it one way, “I would love if insurance companies didn’t fight me as much as they did,” Daniel stated. From ever-changing policies to denied appeals, speech-language pathologists recounted numerous battles fought with insurance companies on behalf of their clients.

“They Changed Their Laws”

When asked what her education could not prepare her for within the workforce, Louise responded simply with, “Insurance coverage. Because it’s constantly changing.” Due to a recent change in Medicare policy, Evelyn recalled recently losing eight clients from her private practice:

Through my company, when Medicare changed their laws two years ago we lost eight [clients] that we were servicing. So it’s [the law] saying that if Medicare wasn't your primary ... your primary had to pick it up first, you had to exhaust all of that before Medicare would pick it up. But if you have a high deductible or you have a high co-pay or whatever, the families can’t afford it. Even if you have Blue Cross Blue Shield or a decent insurance, if you have a high deductible, you're paying through the nose for these services. It's expensive. Families can't afford that. Even some middle-class families can't afford that. I mean if you have a \$3000 deductible, that’s a lot of money.

In Louise’s extensive experience, she has seen at least three major changes in Medicare policy since 1998. With these changes, she has seen that length of stay for patients at skilled nursing facilities has lessened. “We used to keep people longer, but now the insurance companies want people to get home to the next level of care where they can go home with minimal assist and be okay,” Louise stated, “Before we used to work to get more independent before going home ... now they go home and get home care. It's not as expensive, as costly, as being here and getting therapy.”

“Time”

As Louise mentioned, insurance is often the determining factor for the length of

service for recipients of speech/language therapy. Daniel described similar practice within the hospital, “When it comes to an inpatient rehabilitation setting, there are guideline for insurance about how long they’re supposed to be there, and there’s all these metrics and things that say well the recommended length of time 17 days or whatever.” Insurance has the ultimate say, according to Daniel, but hospital workers are able to appeal and sometimes exceed the time period. Louise disagreed with this policy:

I mean people should be able to stay as long as they want, that insurance shouldn’t dictate when you go home. I think that if the therapist says they need another week, they should be able to get it. Sometimes these people need just a little bit more time and they need to – especially with significant strokes – that the progress is slower, more gradual than leaps and bounds. They need to understand how that works.

Becca experienced similar restrictions within the private clinic. She recounted a time when one of her client’s insurance plans had changed without the clinic’s knowledge so that their previously unlimited visits were restricted to around 20-30 for the entire year, causing them to exhaust their visits extremely early in the year. Becca said, “I wrote appeals and I was trying to say like, ‘Listen these kids need the therapy. They need more visits than just the 30 or whatever they’re getting,’ and I tried to make a case for them”. The insurance was less than agreeable, never actually giving her a real response. Everytime she sent in paperwork, they would tell her that she was missing more information. This went on for months, until “Eventually they’re like, ‘Oh well, you’re past the point where you can appeal.’” Becca continued, “I wouldn’t say that was totally a

denial, but it kind of just fizzled. And I feel like it was going to be denied, I was getting the runaround so much that it just wasn't going to happen."

"Go to the Schools and Get It for Free"

There was a shared consensus among all of the participants with significant pediatric experience that school-based therapy services are often insufficient for children with severe disorders or delays. However, as Simone stated, "Insurance just isn't going to cover it when you can go to the schools and get it for free. As Daniel additionally remembered from his time in the outpatient hospital setting, "The thing you run into a lot is that certain insurances – some are better than others – often times say, 'We're not going to pay for outpatient therapy because this child could get it free in the schools.'" He pointed out, "The majority of families, if they aren't getting insurance, they're not going to private pay for services."

The issue with relying on the schools solely to provide speech/language intervention, according to Daniel, is that "Often times, through no fault of the people working in the school, they don't have the time to provide the level of services that were necessary." He claimed that even in the school that he did an internship with, which was in a wealthier district, "I don't know if all of those kids were getting as much as they needed, and they were in a district that probably had more resources." Evelyn, in her 10 years working in the schools, testified to this: between having to do IEPs for every student in a caseload of 70, various other meetings, and being a resource for other teachers, she said, "All of that plays into how are you giving direct therapy and how much time are you giving those kids." Evelyn broke down the actual therapy time:

If you think about it, 30 minutes: you have to walk down to your room, you get them in there, they're all talking, they all want to share something with you. At the end, you have to wrap it up and get something back from them. Like, you know, 'What did we learn today? How are you going to do this outside of here?' You're doing some of that with the older kids too. So really you're opening, you're closing, you've probably got like 20 minutes of therapy. For four kids.

Furthermore, services received through the schools typically do not extend throughout the summer. In Evelyn's experience, she has only seen extended services granted to two or three kids in her district, with requirements being: "One, they have to be in services for a full year. Two, you have to show that they had so much summer regression, they were unable to recoup that summer regression by the end of the first marking period."

This just does not cut it for kids with more severe conditions, as Daniel pointed out, "It was often times kids with really severe phonological disorders, that kind of thing." He particularly remembered one child: "I had a kid who was 6 or 7 but he had like every phonological process. So I was like this is a situation where you need more than 20 minutes twice a week in school in a group." Simone, who saw similar denials in her outpatient hospital setting, shared these thoughts:

We have had kids who have had tumor resections and have been denied therapy. Or kids with cleft repairs – okay this child has had a cleft repair. We really need therapy to work on changing the resonance of their speech or coming out of compensatory strategies to more consistent, clear, intelligible speech. That has required a lot of fighting because insurances fight back saying to take the child to school. School therapists can't handle that.

In Daniel and Simone's experiences, kids needed more support than what schools had to offer, but insurance companies refused to see that.

However, according to Evelyn, "Definitely, the people with good insurance are getting outside services as well." She said, "That makes a huge difference," because they are then able to get one-on-one sessions that are 40-45 minutes long, as opposed to the 30 minute group sessions in the schools. At one point, when Evelyn was simultaneously working in the schools and a private clinic, she had a client in the clinic that was working on the same goals as a student in school. Both children started at approximately the same time and at the same level, but the child in the clinic was able to be dismissed from services within three months, while the child in the school was nowhere near that.

"How They Present on Paper"

Another difficulty that came up repeatedly among the interviewees was that of effectively portraying clients to insurance companies in order to successfully appeal for services. Daniel mentioned that there was "a certain way of phrasing things that seemed to increase the likelihood that they would get accepted" although he was never able to make any successful appeals. The issue, Simone pointed out, is that insurance companies needed "to understand that how a child presents on paper is not always an accurate representation of what the child really is capable of." She remarked that majority of the time, the people in these roles are not clinicians, and as such, "They just assume, 'Oh this child is developmentally appropriate' or 'Oh, this child should be able to do x, y, and z,' and it's not that clear-cut." Louise noted similar frustrations in the skilled nursing facilities, where she has had to let go of "people who have rehab potential and maybe aren't making their progress as quickly as what the insurance company would like."

Becca described a specific instance within the outpatient hospital setting in which a client's insurance refused to cover speech-language pathology services for him. She exclaimed, "This kid was completely non-verbal, he had very poor attention and didn't engage with others at all. Seriously, if you were to spend five minutes with him, you'd be like, 'Oh! Sign this kid up for some speech therapy!'" The family was able to eventually obtain additional insurance through a Medicaid waiver, but Becca expressed:

It was a long process in between. I mean this kid is like two, he's at a crucial age for developing language, and meanwhile we're dealing with insurance for 6-8 months, fighting with them to get services. He's missing half a year or more of really important language development time, and it was just horrible. Then when he came back he didn't really have any more skills. He hadn't really progressed. Simone had a situation where insurance would not grant a child an assistive technology device "because he wasn't showing improvement." However, Simone added, "He didn't have a device to take home with him. So it's like how are you denying him when he can only practice if you're at home – you never gave us a trial. You denied the trial." She stated that there are various reasons why insurance will deny to provide assistive technology. They may think, "Like if the child is verbal, 'Why would you want a device?' Well, some kids are verbal at the one word but can't string sentences together." It comes down to their lack of understanding and knowledge regarding the field.

Family Dynamics

Unsurprisingly, variables regarding the family of a client were consistently highlighted by the participants as often affecting how they receive services. This was more noticeable in settings where clinicians regularly interacted with families, such as

pediatric outpatient settings, although family dynamics had certain effects across all settings. As Daniel expressed, “Family support is obviously a huge deal for a million reasons.” Dedication to therapy, access to transportation, education, and willingness to advocate are some of the reasons verbalized by the speech-language pathologists that family is such a significant factor.

“They Had Other Things to Worry About”

The participants discussed how often times speech-language pathology services are not a priority for families of clients, especially lower-income families. Evelyn noted that her expectations as a therapist were too much for some families, considering “their main concern is living day-to-day. Like, ‘How am I going to put food on the table, how am I going to give them clothing, how am I going to keep this life running?’” She said that things like completing homework and reinforcing use of communication devices were “low on the totem pole for them.” Becca disclosed that many of her clients at the hospital outpatient clinic had been victims of abuse and were part of adoptive or foster families. As such, “there was just that extra baggage that these families brought.” Simone claimed, “It doesn't matter that they're low-income, if they're involved in the process, those children always do better than those families who are not.” However, she acknowledged, “I would say in higher-income districts, families are more invested ... Sometimes we have families who don't see the value in therapy. They don't show up. But a lot of times, it's trying to juggle life as a whole.”

The result of this was often one of two things: families missing sessions in non-school settings or a lack of carryover into homes. Evelyn discerned that for lower socioeconomic status families, “They sometimes can't manage everything ... They're

balancing so many things in their life, they have other things going against them ... Lots of cancellations, no transportation, lots of illness.” Becca mentioned that her hospital clinic had a limit on no-shows before discharging clients, which ended up happening quite frequently. “I think families just got caught up,” she said, “They had other things to worry about. So it was sad because like these kids needed services but policy was we just had to discharge and sometimes we would be a little lenient on it.” For the families carrying “extra baggage”, she said, “You just have to try and serve these kids as best as we can and then also know that their home life might not be the greatest and there’s probably not going to be a lot of carryover.” According to Simone:

It's what they put it in, what the family puts in and what I put in that kind of shapes with this looks like. If I say I'm just going to give mediocre therapy, then I get mediocre results. If I give my all and say ‘Hey, Mom, you got to do this at home,’ but if Mom does not follow through and I gave my all in therapy, I can say, this is how the patient performs, we have no carryover because the family environment is not supportive of this.

Evelyn would also see effects in terms of low-income families failing to access therapy services specifically geared towards them, such as the government-funded programs of Head Start and Great Start Readiness Program. Such programs require families to fill out applications and paperwork, update shot records, and make doctor’s visits prior to admittance. Evelyn commented, “In some cases for the family that's a huge burden and so they can't be bothered by it.” She pointed out that families may not have the time or ability to fulfill all the requirements. For example, “Great Start Readiness, the application is online. So you then have to have access to a computer and the internet.”

Effects are not as apparent in skilled nursing facilities and acute/inpatient hospital settings. However, Louise remarked, “Some families are a little bit more involved than others.” This effects the discharge of patients, as “it's putting a lot of responsibility on the family members to have them be at home.” In such instances where family support is lacking, Louise stated, “Sometimes in those instances they do let them stay a little bit longer. Kind of. They try to look at everybody individually.” Daniel additionally claimed that family support is often necessary for discharging patients from inpatient settings, and to help with providing health information for patients in acute settings.

“Transportation Difficulty”

One of the most common struggles experienced by families was that of access to transportation, according to the participants. Evelyn noted that transportation was another factor that impacted families’ access to programs such as Head Start and Great Start Readiness Program, “Are you living in an area where you have to drive that trial every day? Do you have transportation? Some districts will bus them, others won't ... the driving force behind getting them there has to be the parent.” Becca stated that for low-income families, “A lot of them had transportation difficulty, so they have to cancel a lot. They might only have one car or they have to split amongst the family or that one car breaks down or whatever it might be.” This often resulted in families getting discharged due to missing too many sessions. Daniel experienced the same thing in his outpatient setting, “The other thing that happened not infrequently, is people not showing up due to like transportation issues. So there was a policy that if someone no shows x amount of time, you have to discharge them.” He pointed out that this was a tricky situation, “The question is why aren’t they coming routinely? Whether it’s they don’t have reliable

access to transportation ... So trying to call people from time to time, but at a certain point, you can't call everyone every single time." When discussing factors that influence how successful therapy is, Simone stated:

We don't have transportation so relying on public transportation and public transportation is not reliable so you missed your appointment. So that influences therapy sometimes, and then kids just not coming. But they have no control over that. It all boils down to: 'Mom needs to bring me', 'Dad needs to bring me', 'Grandma needs to bring me'. So there are just things that prevent that, [one of] the big ones being transportation.

“Families Don’t Know What Their Rights Are”

Another issue commonly affecting families, according to Simone, is “parent education ... and then your willingness to fight for your child.” She said that children may be unfairly denied services or not given enough therapy time in the school, “But [parents] don't know how to fight that. Just common-sense education says this is what needs to happen. Where the families in low-income districts just say, ‘Whatever. I'm just glad he's at school.’” This is often because, she said, “You can fight for more, but a lot of times families don't know what their rights are.” Simone stated that this varied among districts, however. When she worked in a low-income school district outside of Michigan, it was much different: “The families knew their rights. Anytime they felt something wasn't going right, and this was a low-income district, they were calling due process.” However, the district within Michigan that she worked in, “Families didn't know their rights ... And you can't tell me no one's ever told you because you got those documents but you just chose not to read it.” She added, “Or you just trust that the school

has your child's best interest at heart and sometimes that's not the case; no one wants children in special-ed because it's more work." She stressed the importance of fighting these battles: "When you keep fighting, school districts eventually concede, because it's easier to concede than to battle with you. But families just won't go to battle, so we settle for 30 minutes a week in a group just doing nothing."

Evelyn also expressed that often times families "don't have the understanding or the educational level to even understand what it is that you're doing." It's hard for them to prioritize therapy or carry it over if they lack the understanding of it, so Evelyn said, "A lot of times, I try to leave very simple things or I try to have the parents sit with us and show them." She noted, "I'm finding I'm getting more participation from the families when I include them and I make it really, almost easy, to do." Simone also remarked, "A lot of it is just the parents need to be educated, and the school-based SLP cannot educate parents because the parents aren't there."

Communication Skills of Speech-language Pathologists

A few of the participants indicated that sometimes the communication capabilities of clinicians themselves may affect the ability of individuals to receive speech-language pathology services or affect how well therapy is conducted. These capabilities can include: empathetic/counseling skills, knowledge of diverse languages, and cultural competence. The effects of such skills on how individuals receive speech-language pathology services can manifest in direct or indirect ways.

"Put Yourself in Their Shoes"

Evelyn revealed one thing she struggled with as a therapist working with underprivileged families: "I always came in high, like 'We're going to do this,' and then I

was crushed when it didn't happen, and I was frustrated and I'm like 'Why can't this family just get it together and do this?'" Things like parents not showing up for IEP (Individualized Education Program) meetings or missing sessions caused her to wonder, "Why do they not care about their kids?" However, she realized, "They're not doing it because they don't want to, they're not doing it because they just can't." This was something that she said she learned through experience, rather than being taught in school. Louise and Becca also mentioned the lack of counseling courses in their speech-language pathology education, which may have helped with this. Becca expressed that it was important to "meet people where they're at and kind of put yourself in their shoes and realize that they might be trying their best even though it doesn't look like it."

Simone disclosed that she felt as though many clinicians within her outpatient clinic were not empathetic to families and parents. She remarked that clinicians, especially those who are not moms themselves, will often "cash judgment" and assume that mothers of their clients are lazy and not doing enough, when the reality is "If she's saying she doesn't have time, it's your job to troubleshoot with her to figure out how to make time for it or to incorporate it into her daily routine." She stated the importance of being an "empathetic listener", because, "When you take on that 'Let me help you, I'm not here to penalize you. Let's work as a unit to figure this out,' families become open and they'll give you information that gives you light into a situation." Simone recounted one instance in which this was particularly crucial:

As a black therapist, I have a black mom who abandoned her home the morning of therapy. The white therapist was like, 'We've got to take them off the schedule. Mom keeps coming off and won't show up.' But when mom called and spoke to

me, she was in tears. And she said, 'Here's the situation. I've been fighting for my life for the past 2 weeks. Sometimes I've just been trying to get it together. And by the time I get it together, he's back at the house and it's hard for me to escape. He doesn't think the baby needs to get therapy.' I know he does, the baby has Down syndrome, non-verbal and fine motor skills. But she called me that morning. She said, 'I left today with just the clothes on our back. I'm at a shelter.'

Simone told the mom that her safety was priority and put her on a three week break in order to recover from the events and settle down. The mother called back after three weeks and resumed therapy. She commented, "It's in those situations when you show like, 'Hey, I care. Hey, I'm listening. Hey, I understand,' the families open up and they'll give you the real story instead of those fake reasons as to why they're not engaging." She said it's important to understand that "they're here because there's some skill that we have that the parents don't have. And it's our job to empower them to use that skill."

"People Who Don't Speak English"

According to Daniel, "One thing that comes up as far as underserved populations is people who don't speak English." While working in the acute and inpatient hospital setting, he has occasionally encountered people who speak minimal or no English. He said, "If it's a swallow evaluation and they speak some English, usually you can do it," however, "If it's a stroke and they have Aphasia, then it's a different type of thing. And it's frustrating in terms of there are just some inherent limitations." For one, Daniel heeded the shortage of interpreters, which makes it difficult to schedule them and often results in long waits. Although even with access to one, Daniel claimed, "Language therapy through an interpreter is just never going to be as good." He said that he tries

with his “broken Spanish”, but the fact is, “It’s never quite as effective, because you can’t treat the nuances. Part of what you’re doing is the little things, and you lose those nuances through an interpreter.” There is not much that can be done on the end of clinicians in terms of this, as this is “one of those general weaknesses in our field,” as Daniel put it, “that there aren’t a lot of speech-language pathologists from minority backgrounds who speak Arabic and that kind of thing.” Simone also pointed out that within her outpatient setting, a lot of the clients are Arab or Hispanic, but she said, “I am one of four black therapists here. There’s one Indian, no Arab, and No Hispanic. So already we are at a minority in therapists based off of the cultures we see.”

“Know What Their Cultural Norms Are”

In order to be a good speech-language pathologist, Daniel advised to “Learn things culturally.” Simone heavily emphasized the importance of cultural awareness when working with underrepresented populations due to her own firsthand experiences as a black speech-language pathologist working with many racial/ethnic minority children. She stated, “Know what their cultural norms are. You cannot expect the families to adjust to you ... it's being aware of those things and understanding you're not going to change someone's cultural norms or their community norms.”

Simone provided several examples demonstrating the importance of cultural awareness. The main one she discussed was feeding within African-American culture: “Did a lot of low-income minority parents have access to these fancy grinders? No, we chewed it [meat] up, gave it to the kid.” As such, she said, “You can’t expect an African-American mom to stop chewing meat and putting it in their mouth. Like historically, that's what they've done. My grandmother used to do it for me and my mom did it for

me.” Rather than condemn or ignore the cultural practices and traditions of families, Simone stated, “When you go ‘Yes, I acknowledge this and under no means do I want you to change your community or your cultural practice. However, Johnny needs something a little different.’ Then families are more receptive to that.” Other examples Simone pointed out were being careful not to mention birthdays and holidays around Jehovah’s Witnesses, and being mindful of the fasting period for many Arab families. “We don’t want to have a child who needs to do a language assessment if they are of age to do this fasting. Having him do that and he hasn’t eaten is not going to benefit any of us,” she noted, “Let’s start this eval after the fasting period is done. Because we want to make sure we capture him at his best.”

Prevalence of Services

While it was not explicitly stated by all participants, it was implied by all participants that none of them knew much about speech-language pathologists growing up, and their exposure to the speech-language pathology prior to pursuing the field was extremely limited. Becca, Evelyn, and Louise found about speech-language pathology as teenagers: Becca due to the younger sister of a close friend having received services, and Evelyn and Louise through children that they babysat having received services. Simone and Daniel did not find about the profession until they had already begun college and ended up switching majors to pursue it. As Evelyn stated, many children growing up are unaware of the profession of speech-language pathology as opposed to professions such as nurse or teacher, “unless somebody’s had something tragic in their life where there’s been an accident to a family member, or they have a family member with autism.”

She cited the low prevalence of speech-language pathology services and lack of knowledge regarding the field as a whole among the general population as another factor that may impact accessibility.

“We Should Be More Widely Known”

According to Evelyn, due to the lack of knowledge people have regarding the field of speech-language pathology, they may struggle to access services. This is especially a problem for low-income families, she claimed, who may visit clinics rather than a regular pediatrician to properly follow the development of the child so “the parent may or may not even be aware that there's an issue.” Many families are not aware that these services exist and that there are free programs out there for them. Evelyn recalled telling four different families about birth to three programs that they had otherwise never heard of. She asked, “How do we get the word out that, you know, speech therapy is available from birth? If your child develops something a year later, you won't even know that those services are available.” Becca also recounted having to convince a family at her private clinic to obtain speech services for their child. Evelyn stated, “We should be more widely known.” Especially for children who are receiving services, she said, “If we're making dolls and all of these things for children to learn about the important helpers in their life, these community helpers, these occupations, well the speech therapist is just as important as the police officer.”

“They Don't Offer Speech Services”

Evelyn also expressed her desire to see more government-based facilities offering speech-language pathology services, such as Community Mental Health in Michigan. She pointed out that even among the Community Mental Health facilities, “some of the

counties within our state, they don't offer speech services. Not every county does.” She reported entering one specific county just a couple months prior to the interview, and it had been the first time that they had ever been able to offer speech-language pathology services. “How can you not be offering that to your most severe children within your county?” she asked, “How did you go so long and not have that for them?” She said it was exciting for them to now be able to offer such services, but she wondered how many other counties lacked them, noting at least one other county in Michigan that she knew did not offer speech-language pathology services.

Conclusions

According to the findings of this study, common factors affecting the accessibility of speech-language pathology services were: insurance, overall family dynamics including socioeconomic status, communication skills of speech-language pathologists, and prevalence of services. All of the participants particularly emphasized insurance and family dynamics as the major factors, while some of them additionally described factors regarding the communication skills of speech-language pathologists and the prevalence of services. This confirmed much of what was established within the reviewed literature.

In terms of insurance, Mc Manus et al. (2018) discovered that children who had had been uninsured within the past year experienced double the likelihood of lacking necessary therapy services those who had been unceasingly insured. Participants noted that in terms of speech therapy services, this meant being denied services beyond the school setting. As Daniel said, “The thing you run into a lot is that certain insurances – some are better than others – often times say, ‘We're not going to pay for outpatient

therapy because this child could get it free in the schools.” One study conducted within the state of Kentucky found that for Medicaid children, uncovered expenses for speech-language pathology services were much greater than they were for privately insured children (Young et al., 2009). This may be due to the lack of coverage beyond the school setting. However, Benedict (2006) found that the likelihood of accessing therapy services outside of school was over twice as much for children with public insurance than privately insured children. This did not match Evelyn’s experience, as she said, “Definitely, the people with good insurance are getting outside services as well.” The wide range of different public and private insurance policies and types may be the cause for this.

When it came to family dynamics, Benedict (2006) found that having someone with post-high school education made families more likely to identify a need for therapeutic services, and as such increased access to services. Similarly, Simone noted “parent education” as a major factor affecting families. She stated, “Just common-sense education says this is what needs to happen. Where the families in low-income districts just say, ‘Whatever. I'm just glad he's at school.’” Evelyn also mentioned how she noticed that families often “don't have the understanding or the educational level to even understand what it is that you're doing.” Additionally, individuals from low socioeconomic statuses were much less likely to have contact with doctors in the United States and Canada (Blackwell et al., 2009). Evelyn pointed out that due to the lack of contact with doctors, low-income families “may or may not even be aware that there's an issue.” She said, “Whatever clinic they're walking into, or they might even be going to the health department to get their shots, those facilities aren't tracking that child's

development appropriately and therefore they're not referring them out to others.”

Furthermore, family socioeconomic status for children with cochlear implants correlated with reduced presence for follow-up appointments, essentially resulting in worse speech/language outcomes (Chang et al., 2010). As said Becca recalled, “There were several kids that I had to discharge based on their attendance.” Daniel also noticed when working with low-income populations, “The other thing that happened not infrequently, is people not showing up due to transportation issues.”

Research regarding communication skills of healthcare providers found that non-English speaking patients struggled to communicate with them even with interpreters, and as such suffered a lack of understanding in terms of medical conditions and therapy (Raynor, 2016). This resembled what Daniel mentioned: “Language therapy through an interpreter is just never going to be as good.” As far as the prevalence of services, it was found that geographic location affected this, with urban areas having far more available speech-language pathology and behavioral therapy services than less urban areas (Monz et al., 2019). Evelyn similarly noted, “Even some of the counties within our state, they [Community Mental Health] don't offer speech services. Not every county does.”

Greenwood et al. (2006) additionally determined that among students in the UK, only about one-third knew what speech-language therapy was and over half did not know that speech-language pathology was an educational route. These numbers were even higher for males and ethnic minorities. This matched what Evelyn stated: “When you tell someone you're going to be a speech pathologist, how many people ask you, ‘Well, I don't even know what that is.’” In regards to the lack of diversity, Daniel said, “That's

probably one of those general weaknesses in our field, that there aren't a lot of speech-language pathologists from minority backgrounds.”

Implications

There are a number of implications arising from this study. Firstly, the findings point to the necessity of insurance reform in terms of providing therapeutic services. As participants pointed out, insurance companies are often overly restrictive and lack knowledge regarding speech-language pathology services. Insurance companies should be receptive to input from clinicians, or hire more clinicians to provide insight in making decisions regarding coverage. Government agencies also need to do more in terms of providing services for low-income families and minimizing barriers such as transportation. The findings additionally indicate the necessity of counseling and cultural competence classes within speech-language pathology education in order to be properly accommodating towards clients. Participants stated that there should be more communication with parents within the schools in order to allow for more carryover and help parents be more informed. They also implied the need for more diverse speech-language pathologists in order to improve access to service for racially/ethnically diverse and non-English speaking clients. Finally, the findings indicated the necessity of raising more awareness regarding the field of speech-language pathology among the general public so that families are able to understand and seek out such services more easily.

Limitations and Suggestions for Future Research

This study had several limitations, primarily related to the small sample size. Firstly, the number of participants in this study was extremely limited, with one to four participants for each setting. This made it difficult to provide a fair representation of the

experiences of speech-language pathologists within the different settings. There is also no more than one speech-language pathologist from each individual workplace, so their experiences cannot be confirmed by colleagues. Furthermore, the speech-language pathologists all hail from the same region, which restricts any findings to the particular region. The nature of the convenience sampling method that was used may have also resulted in bias in terms of participant selection. It should be noted that due to the limitations of this study, no generalizations or applications to a wider population can be made. The findings of the study merely point to major patterns and themes in issues of accessibility as perceived by several speech-language pathologists in southeast Michigan. They are intended to provide insight for prospective and current speech-language pathologists as well as individuals interested in public health policy, rather than serve as evidence for particular issues.

Future research may include a wider range of participants, such as across the state or even across the country to see if experiences vary across the region. Another suggestion would be to incorporate more participants from each of the settings within the same region in order to have more reliable results. Future research may also choose to focus on pediatric settings versus adult settings, or only one type of setting to more accurately depict trends within specific settings. It may also be helpful to include more racially/ethnically diverse speech-language pathologists as participants to highlight their unique perspectives.

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Appendix A: Interview Questions

1. Tell me about your personal experiences that led you to become a speech-language pathologist.
 - a. Follow-up questions as appropriate
2. Tell me about your educational background.
 - a. Follow-up questions as appropriate
3. Tell me about your professional background.
 - a. Follow-up questions as appropriate
4. Tell me about your current job.
 - a. Follow-up questions as appropriate
5. What experiences have you had with members of underserved populations at your current and past jobs?
 - a. Follow-up questions as appropriate
6. What would you wish to change about the accessibility of speech-language pathology services for members of underserved populations?
 - a. Follow-up questions as appropriate
7. What advice would you give to a new speech-language pathologist who is soon to be working with members of underserved populations?

Appendix B: Recruitment Letter

Hello,

I hope this email finds you well! My name is Maymuna Jamil and I am a senior in the undergraduate Speech-language Pathology program at Eastern Michigan University.

I am writing to you regarding the research I am conducting for my senior thesis. I would like to invite you to participate in my study about the accessibility of speech-language pathology services for members of underserved populations, entitled: Selective Service: Experiences of Speech-language Pathologists Serving Underrepresented Populations.

You are eligible to be in this study if you are an SLP-CCC and have had significant encounters with members of underserved populations (low socioeconomic standing, Medicaid/Medicare, uninsured, homeless, etc.) while practicing.

If you decide to participate in this study, you will participate in:

- One audio-taped interview, roughly 1 hour in length in which the investigator will ask questions about your personal experiences and reflections. The interview will take place in a private, mutually agreed upon space and time and may occur in person or over the phone.
- Additional interviews may be requested, lasting 15-30 minutes in length, for further questions and clarification about interactions with members of underserved populations in terms of speech-language pathology services. These interview(s) will also take place in a private, mutually agreed space and time and may occur in person or over the phone.
- The total time of participation in this study will span approximately three hours, maximum.

I will then use the information gathered to create a summary report.

Remember, this is completely voluntary. You can choose to be in the study or not. If you'd like to participate or have any questions about the study, please email or contact me at mjamil@emich.edu.

Thank you very much. Sincerely,
Maymuna Jamil

Appendix C: Informed Consent Form

The person in charge of this study is Maymuna Jamil. Maymuna is an undergraduate student at Eastern Michigan University. Throughout this form, Maymuna will be referred to as the “investigator.”

Purpose of the study

The purpose of this research study is to explore the experiences of speech-language pathologists that treat underserved populations, such as those who may be uninsured, low socioeconomic standing, homeless, etc.

What will happen if I participate in this study?

Participation in this study involves

- One audio-taped interview, 1-2 hours in length in which the investigator will ask questions about experiences and reflections on experiences in providing speech-language pathology services to members of underserved populations. The interview will take place in a private, mutually agreed upon space and time and may occur in person or over the phone.
- Additional interviews may be requested, lasting 15-30 minutes in length, for further questions and clarification about interactions with members of underserved populations in terms of speech-language pathology services. These interview(s) will also take place in a private, mutually agreed space and time and may occur in person or over the phone.
- The total time of participation in this study will span approximately three hours, maximum.
- I would like to audio record you for this study. If you agree to be audio recorded, sign the appropriate line at the bottom of this form.

What are the anticipated risks for participation?

Participation in the study might increase your recollection of periods of frustration or helplessness during your experiences with members of underserved populations. If you are audio recorded, it will be possible to identify you through your voice. If you do not agree to be audio recorded, you may not be eligible to participate in this study.

Are there any benefits to participating?

While you will not directly benefit from participating in this study, this experience may present an opportunity to reflect on your own perceptions and experiences of interactions with members of underserved populations.

How will my information be kept confidential?

The interview audio recordings will be kept locked in a filing cabinet in a key-locked office. The interviews will be audio recorded using two personal audio recorders (one for back up purposes). The audio recordings will be labeled with pseudonyms. Only the investigator will have access to the pseudonym/real identity key. Transcription will be completed, with pseudonyms and fictitious demographic information in place, from a reputable, professional transcription service. The transcriptionist is knowledgeable of health insurance portability and accountability act (HIPAA), family educational rights and privacy act (FERPA), and institutional review board practices for protecting patient identity.

The transcriptions will be locked on password-protected file on a password-protected computer. If printed, they will be placed in a locked filing cabinet in a key-locked office.

Dissemination of Results

The results of this study may be disseminated at professional conferences, conventions, or meetings as well as via professional journals, book chapters, books, or similar venues. Fictitious names will be assigned in any report to all participants, their place(s) of employment, and any other identifying information.

I can elect to be notified when the study is published by signing the appropriate line at the bottom of this form.

Study contact information

If you have any questions about the research, you can contact the Principal [Investigator, Maymuna Jamil, at \[mjamil@emich.edu\]\(mailto:mjamil@emich.edu\)](#) or by phone at 734.664.8225.

For questions about your rights as a research subject, contact the Eastern Michigan University Human Subjects Review Committee at human.subjects@emich.edu or by phone at 734.487.3090.

Voluntary participation

Participation in this research study is your choice. You may refuse to participate at any time, even after signing this form, with no penalty or loss of benefits to which you are otherwise entitled. If you leave the study, the information you provided will be kept confidential. You may request, in writing, that your identifiable information be destroyed. However, the investigator cannot destroy any information that has already been published.

Statement of Consent

I have read this form. I have had an opportunity to ask questions and am satisfied with the answers I received. I give my consent to participate in this research study.

Signatures

Name of Participant

Signature of Participant

Date

I agree to be audio recorded for this study.

Signature of Participant

Date

I would like to be notified when the study is published.

Signature of Participant

Date

Participant email address

I have explained the research to the subject and answered all his/her questions. I will give a copy of the signed consent form to the subject.

Name of Investigator

Signature of Investigator

Date