Public Policy and Advocacy Department began working on the Community Voices for Medicaid (CVM) project in February of 2020. The goal of the project was threefold:

1. Engage with St. Louis community members in meaningful ways;
2. Provide a platform for people with disabilities to share their stories and Medicaid experiences with providers/practitioners and community members;
3. Educate the community at large about the importance of Medicaid.

The original plan was to engage the community with several in-person events at Paraquad’s social enterprise coffee shop—Bloom Café. In addition to hosting events, the team planned to attend community events/gatherings to share resources about Medicaid.

However, in March 2020, everything changed. With the onset of the COVID-19 pandemic, Paraquad and the rest of the world shifted to 100% virtual. This created a lot of barriers and headaches; but with creativity, Paraquad was able to adapt and still host events to meet the goals outlined in the CVM project. Even though all the events had to be virtual, we were still able to host several informational story-sharing events.

This book will highlight those events and share the stories of our disabled Medicaid ambassadors and the community leaders who supported this project.
Paraquad’s first event was a story-sharing session that highlighted two disabled women with similar disabilities and educational experiences. Ellie and Gabriella both have the same form of muscular dystrophy, they both went to the University of Missouri for their undergraduate degrees, and they are both now in law school in St. Louis.

Ellie grew up in Colombia, MO and Gabriella grew up in St. Louis.  Ellie is in her second year at Washington University School of Law and Gabriella is in her third year at Saint Louis University Law School. The women shared their experiences growing up with a disability, going to school, and living independently. They also discussed why they chose to go to law school and what they wished they had known about Medicaid and using personal care attendants in college.
Meet Gabriella
As a young child, Gabriella was diagnosed with Spinal Muscular Atrophy Type 2 and has been a wheelchair user since the age of two. During her time as a law student at St. Louis University, Gabriella heard about Paraquad. Paraquad has benefited Gabriella in two major ways: advocacy and community. Gabriella described how Paraquad “has her back” by working diligently to keep tabs on any legislation that would do injustice to the disability community and actively advocating against such discriminatory policies. Paraquad has also provided a sense of community that Gabriella had not experienced before through connecting with others who have shared her experiences and building an amazing support system of true friends. This contrasted with the past experiences Gabriella spoke of having, such as going through life being told how different she was and being treated as if she “needed to be fixed.” She described discovering Paraquad as an “unbelievable sense of relief.” Now on the board of directors at Paraquad, Gabriella commends the Center for Independent Living’s ability to compile abundant resources and connect the disability community without pushing a specific agenda.
Outside of Paraquad, she also receives benefits and assistance through Medicaid. However, Gabriella is attuned to the many challenges of Medicaid. The Medicaid Waiver and consumer-directed services (CDS) are instrumental to her daily routine: from the moment she wakes up in the morning to get ready for the day, to participating in law school classes, until she ends the day at her own home. Despite this, the disability community’s needs are not placed at the center of Medicaid. Foremost, Medicaid Waivers are poorly advertised. Gabriella heard about it through word-of-mouth and has received backlash from program administrators for trying to share information about the waiver program with friends who face similar barriers. Secondly, when considering colleges, Gabriella was forced to stay in-state due to the fact that her waiver program does not transfer well between states; moving out of state would have put her on a waiting list for services that are necessary for her daily life. Moreover, having this waiver has not guaranteed Gabriella everything that she needs and wants. She describes experiencing constant cuts to CDS hours. Additionally, there are social and financial implications to the Medicaid Waiver. As she poignantly expressed, “If I get a job, I lose everything. If I get married, I lose everything... I can’t have a savings account because I will be taken off Medicaid.” Gabriella stated that a myriad of changes must occur with the program. Federally executing Medicaid, eliminating income caps, and changing how marriage affects service eligibility is merely the beginning, but it would be a start for her. In the end, Medicaid is a double-edged sword for Gabriella. While the attendant services are crucial for her, she admits, “As an adult, I feel like I’m not being treated as an adult.”
Meet Ellie
Ellie’s Story

Ellie is an outgoing 24-year-old who has been a Medicaid recipient for the past six years. “If I didn’t have Medicaid, I’d still be living with my parents.” Ellie went to college at Mizzou and is currently in law school at Washington University. She loves the independence her Medicaid programs afford her, “I can’t overstate how good it is to be like every other adult human and not live with my parents.” To maintain her independence, Ellie uses the Medically Fragile Adult Waiver to find in-home aids and overnight nurses. Thinking about what life would be like without Medicaid is “not great” for Ellie. Her parents are aging, and she knows they won’t be able to assist her forever. Aside from restrictive income caps and asset limits associated with Medicaid, Ellie also struggles to maintain full nursing coverage, meaning many of her hours go uncovered. This is frustrating and unsafe, “A few weeks ago, I had to have a stranger help me because my nurse called off last minute and I needed to be able to go to the bathroom.” Often, the agency Ellie works with makes her feel like they do not care if her nursing shifts are covered or not. Ellie believes that higher pay for nurses and PCAs would make it easier to get services. In addition to needing more funding, Ellie believes that eligibility requirements should be less restrictive and services should be more flexible. For example, “Some days I need more help than others and I should be able to schedule my nurses and attendants around my needs, not the other way around.” Despite the program’s shortcomings, Ellie is grateful for the independence and increased quality of life Medicaid has allowed her to have.
Twitter Chats

Early in the pandemic, many people in St. Louis did not have access to Zoom or other video conferencing technologies. Sean Gold, Medicaid Ambassador and St. Louis-area leader has a large following on Twitter. He agreed to share his story in an interview-style Twitter Chat, to make sure people who did not have access to new technology could learn about the importance of Medicaid. In addition to the Chat with Paraquad, Sean also participated in a Twitter Chat with North Carolina AIDS Action Network (NCAAN), another organization participating in the CVM project. The second event amplified the voices of marginalized individuals with intersecting identities and highlighted the importance of access to Medicaid for LGBTQIA+ individuals. During this event, Sean was able to discuss his experiences as a gay, Black, disabled man and share information with his network, Paraquad’s network, an/d the NCAAN network.
Meet Sean
Sean’s Story

Sean Gold is a 22-year-old St. Louis native, published author, public speaker, and content creator. Sean’s interests include reading/writing fan fiction and building power within the disability community. He wants to be a leader for disability rights and social justice within his community.

His desire to connect with others led him to get involved with Paraquad. In 2017, he joined the youth group program. During the program, leaders realized he was excelling in the topics and Sean was able to occupy a mentorship role for his friends in the group.

Sean is currently on Medicaid and has been for the past 20 years. He recently realized he is also covered by Medicare. Medicaid pays for his in-home care attendants and health supplements. Sean gets up around 9-11 AM each day and drinks two Ensure from his bed. After that, his mom makes him breakfast which he eats with a curved spoon. Every morning, his care attendants help him get up out of bed, shower, dressed, and ready for the day.

Although Medicaid covers many medical services that help Sean maintain his independence, it is a constant battle to fight for the services he needs. Sean reports frustrations regarding the income cap, as it limits how many paid public speaking engagements he can accept without losing his benefits. At the end of the day, Sean recognizes the stigma associated with accepting Medicaid and hopes to move forward with an open dialogue about deconstructing systemic ableism.

The biggest impact that Paraquad has made on Sean’s life is in lasting friendships and community. Sean’s disability has not stopped him from achieving his biggest goals. Sean has a webpage with all his accomplishments and links to his social media platforms: https://linktr.ee/AuthorSeanGold.
Paraquad serves people with disabilities in St. Louis City and County. However, there are Centers for Independent Living across the state. For one of our story-sharing events, we partnered with the nonprofit Missouri Rural Crisis Center (MRCC), another CVM project participant, to make sure their consumers knew about Independent Living and Centers for Independent Living. At this event, Tyra shared her story about how she uses Medicaid to live independently, how Paraquad has helped her meet her independence goals, and how Centers for Independent Living across the state offer similar services.
Tyra’s Story

Tyra Williams has a deep desire to give back to her community. As a person with cerebral palsy, she has successfully found ways to utilize every program she’s been involved with, from her education in the Special School District to her years of working with Paraquad. Tyra just wants to give back.
As a part of remaining an engaged citizen, Tyra understands that she needs support, the type of support that ensures that she can remain as independent as possible! She found that support when she partnered with Paraquad through the Consumer Directed Services program. Through this program, Tyra receives assistance with bathing, dressing, food prep, and much more. As a result, Tyra has been able to maintain a job with Special School District, giving back to a system that gave her so much. CDS has allowed her to use the hours that she would be using struggling to dress herself, feed herself, bathe herself, and put that energy back into the community...working with Special School District feeding children who cannot feed themselves.
Recently, everything that she has worked for in her thirty-three years, and all the good she is doing almost became much more difficult, when her CDS hours were cut from six hours to three hours and forty-five minutes. Tyra began to panic because when she first heard about the cuts before she even felt their impact, her mind went right to the leg treatment that she needs as part of her daily care, which takes up to three hours. She was frightened... how was she going to do all her other basic in-home care tasks and meet this treatment need?
She contacted Paraquad, and in partnership with them, she wrote an advocacy letter. This advocacy letter got Tyra on a much-needed waiver program, which restored her hours. Tyra says she acknowledges what her options would have been had she not gotten the waiver: The nursing home, a place where she recognizes that no person should be, no matter what age. She says it is a place that can strip you of your purpose and kill you quickly. The realization of the fact that many people did not have the opportunity to get on a waiver program, and now, there is a huge waiting list, makes Tyra supremely appreciative that she and Paraquad could work together to make the waiver program possible for her. Tyra wishes that more people with disabilities could be given the opportunity she has been given.
Youth to Adult Medicaid Transition Summit

One of the most confusing times for disabled Medicaid recipients is the transition from youth Medicaid services to the services that fall under the Aged, Blind, & Disabled category. In November of 2020, Paraquad Partnered with Several organizations to host a Transition Summit to educate youth, families, teachers, and other professionals on the transition process. Presenters from organizations including Special School District, Vocational Rehabilitation, and Saint Louis University shared knowledge about resources available to families. Disabled individuals shared their stories about Medicaid in college, and what worked and did not work for them. There were more than 100 attendees, and Paraquad received a lot of positive feedback.
Meet Raven
Raven’s Story

Raven McFadden has a long history with Paraquad. She joined Paraquad’s youth group around age 16. She participated in the group for several years from 2009 to 2012. During her time with the youth group, she learned skills for accomplishing various activities of daily living. Raven also developed her self-advocacy skills, which helped her become a better advocate for herself and others.

Raven transitioned out of the youth group once she enrolled in Fontbonne University. She majored in communications with a minor in sociology and psychology. While at Fontbonne she was the Vice-President of Student Advocacy within the Student Government Association. In this role, she had the opportunity to utilize some of the advocacy skills she learned in the youth group. She advocated for the needs of all student organizations on campus.

Around 2014 she began using Paraquad’s Health and Wellness Center, now the Stephen A. Orthwein Center. She liked that it was fully accessible to her and she had a great experience. That same year, Raven began using personal attendant services through Paraquad’s Consumer-Directed Services program and still does to this day. She would not be able to function without it. Raven chooses to use her family as her attendants. She prefers this because they know her and know what she needs. Her attendants help her get dressed and ready for class, help prepare meals, help with transfers, bathing, toileting, and other activities of daily living.
In 2017, when the CDS program was cut, Raven was fortunate that her Paraquad CDS Specialist assisted her with obtaining additional personal care hours through the Independent Living Waiver.

In addition, she became a peer mentor with Paraquad in 2015. Raven feels that being a peer mentor is very fulfilling and fun. She is honored that people look to her for advice. She is currently mentoring a peer to help her gain skills to use public transit, with the long-term goal of returning to school.

Raven graduated from Fontbonne in 2016 and began a master’s program at Lindenwood in Criminal Justice Administration. She has completed this program and has plans to continue her academic success at St. Louis University’s law school in 2020.

Currently, Raven works 10 hours a week as Paraquad’s youth and family and peer services assistant. She is grateful for the support Paraquad has provided her over the years and believes it has helped her increase her independence. She is glad she could share her experience and help others succeed.
Medicaid Appeals and Legal Resources

There are many rules and regulations disabled individuals must comply with to maintain Medicaid eligibility. Often these rules are confusing, and Medicaid does not provide adequate or accessible information and people must file appeals to ensure they won’t lose their much-needed Medicaid coverage. For this event, Paraquad hosted community leader Luke Barber and Legal Services of Eastern Missouri to discuss what happens when individuals lose access to Medicaid and need to file an appeal to restore coverage.
Luke’s Story


In 2019, Luke was one of 100,000 people who experienced a three month gap in coverage due to a computer error. Luke explained, “IT and computer science professionals refuse to service the IT infrastructure (FORTRAN), and a lot of database software cannot run properly because they are incompatible. As a result, many of the cross-referencing/cross-checking/cross-tabulation where you can see what other programs someone may be eligible for aren’t occurring because the system doesn’t allow it to occur. At the time, I had other benefits that automatically made me eligible, but it didn’t correct it. The state of Missouri cut me for three months incorrectly. Through advocacy groups/adjudicating process, I ultimately proved that I was eligible. It happened to 100,000+ people at the same time. A statewide purge of the list occurred. The system kicked out 100,000 people who were up for review. Many showed up to doctor appointments and were told they did not have it. I received a letter in advance stating that it had lapsed. Most people had no idea why they were cut originally. We were finding the issues with the systems during the hearing processes, so that’s where they figured out it was a computer glitch.” Despite frustrations and technical issues, he is able to use Medicaid to get the services he needs. Recently, Luke has participated in Medicaid-funded job coaching, community support services, and independent living skills training. These services helped Luke prepare for the life of independence he has now. In 2020, he ran for state representative. Luke was disappointed that he didn’t win, but he isn’t done with public service – he is currently studying Policy and Social Work at the University of Missouri – St. Louis, sits on the St. Louis County Commission on Disability, and has his sights set on running for office again in 2022.
Several Medicaid Recipients were excited for the opportunity to share their stories, but could not participate in a story-sharing event due to the pandemic. The individuals highlighted in this section are ambassadors for Medicaid and care deeply about the success of the program.
Ruqayyah’s Story

Ruqayyah’s educational journey has been a bumpy road. In her early years of high school, she said, “The teachers were not listening to me. They said I couldn't go to college.” She was struggling with her education and her school was not making the appropriate accommodations to support her the way that she needed to be supported. It wasn’t until her junior year of high school that her mother thought enough was enough and decided to help her look for educational services that would meet her individual needs. This is where Paraquad stepped in. One of the first people she ever worked with at Paraquad was Stephanie, Paraquad’s Youth and Family Education Specialist, who sat with Ruqayyah, her mother, and staff from her high school and advocated for her education. Paraquad’s youth group provided her with an Individualized Education Program (IEP), a document that enables students to receive the services that they need to excel in school. Ruqayyah explains how Paraquad, “Just told me I could do anything that I wanted.”

Upon graduating from high school, Paraquad helped her apply to college. She has been attending St. Louis Community College-Forest Park since 2010 where she’s majoring in Human Services. While in college, Ruqayyah was met with more roadblocks: paying for her education and actively participating in the classroom. She was never informed that there was a maximum amount of Pell Grant money you could receive throughout your lifetime. When she was told that she had used up most of her money, Paraquad began to financially support her. Because of Ruqayyah’s dyslexia, it is hard for her to read textbooks for class. Paraquad introduced her to audiobooks which have allowed her to be more up to date with her coursework. As Ruqayyah reaches the end of her community college experience, she explains that she plans on collaborating with Paraquad to complete her practicum, “I am going to try to do my practicum with Paraquad. I am going to definitely try to do it with the youth group in the education services in my first year and then in the second year, I'll do it with public policy.”
Ruqayyah’s Story Pt. 2

Ruqayyah is big on public policy, advocating for the disabled community, and teaching herself and others. She is taking a sexuality class at the Brown School at Washington University in St. Louis and also had the opportunity to co-teach a class with Planned Parenthood, “I was so excited and so I did it.” One of the things she is most looking forward to is her TED-style talk, “I have a TED Talk coming up with Sarah about public policy.” In regard to advocating, Ruqayyah states, “I’ve been advocating for change for the disability community since 2008 because I was discriminated against because of my disability. I advocate for change in my community, mostly the disability community because that is what I am comfortable advocating for and know a little bit about, but I am willing to learn how to spread and advocate for other things.” Through Paraquad, Ruqayyah has been able to continue with her education and has learned the knowledge and skills to advocate for herself and for others, which she is grateful for.

Ruqayyah attributes her ability to earn a driver’s license to her connections with Paraquad. She took a permit class through Paraquad and stated, “I took my permit test the twelfth time and got it thanks to that class.” She further explained that the permit class is great, “It is more hands-on, they did drawings of the road.” After passing the permit test, she began using her income from Bloom Café to pay for her driving lessons. Once she was able to complete her driving lessons, she was able to earn her driver's license. She explained, “Thanks to Paraquad, I was able to learn how to drive.”
Ruqayyah’s Story Pt. 3

Ruqayyah started working at Bloom Café, a social enterprise restaurant, in shifts from 6 a.m. to 10 a.m. While there, she learned a lot of valuable work-related skills that she can now apply to her current job. She stated, “I used to work at Bloom Café and boy did I learn a lot at Bloom Café. I was the first employee to walk in . . . I learned so much at Bloom. I learned to deal with tough situations, how to advocate for myself on the job, and work with my job coach. . . Bloom helped me learn so much that I can do it at my new job.” Additionally, she explains that at Bloom Café, she learned how to deal with others, and it helped her develop skills to get the job she now has at Schnucks. Her first boss at Bloom had a major impact on her life in teaching her some of those skills. She said, “I had to learn how to leave my personal life behind and deal with work life and Bloom taught me that because I was going through a lot in my personal life . . . I learned to get to work early and unwind with some music.”

In the community that Ruqayyah grew up in, she was never taught how to understand the laws and rights she had as a person with disabilities. She states that as she was growing up with a disability, “I have been misinformed a lot.” She does not want others to misinform the disabled community and she expressed, “People with disabilities need to be educated just like everybody else.” Paraquad taught her a lot about the laws and rights she has so she can be educated and advocate for herself in her community. She also explained a need for a person with a disability is to be informed just like everyone else. She stated, “It’s refreshing to have a disability because people thought I couldn’t do certain things I do, and now I’m trying to be a sex educator... and I don’t think people with disabilities should be limited, I think we should be treated like everybody else.”
Ruqayyah’s Story Pt. 4

Ruqayyah has been utilizing Medicaid MO HealthNet Services for a long time since her diagnosis with Autism when she was 3 years old. Ruqayyah’s Godfather, Keith, helped pay for the diagnostic testing to receive her diagnosis. Ruqayyah’s long-time advocate and previous case manager at the Department of Mental Health, Bridget B., advocated for Ruqayyah to receive CDS services through Medicaid and Paraquad. Bridget B. also helped her get connected with an individual she called Ms. Pat who taught her so much. She was able to learn about sex, how to wear clothes correctly, how to cook and clean, and how to understand the weather. She explained, “It’s amazing what I have learned having those CDS services with...Ms. Pat because I learned so much in that little bit of time.” Bridget B. further advocated for Ruqayyah to receive a Medicaid waiver to begin to receive DSP services from EasterSeals instead. So although she no longer receives CDS from Medicaid, she states without Medicaid services, “I would not be as advanced as I am.” She shares her opinion that “Everybody who receives CDS services is having a crisis right now” and that pay needs to increase for CDS. She states that “CDS is the ground root and it helps a lot of people who are higher functioning... be productive members of society.”

Ruqayyah currently lives on her own, is happily employed, and continues to pursue higher education. She enjoys working and being able to support herself, and soon enough, she will fulfill her goal of being entirely independent. Ruqayyah is proud of the progress she has made, discussing how far she has come with the support and guidance of Paraquad during her high school years up until now, stating, “And look where I am now; I live on my own. I get support through EasterSeals for DSP services. But soon enough I am going to be able to be on my own.” When sharing her story, Ruqayyah emphasized how much she appreciates the support of Paraquad and how they have guided her through the process of becoming the person she wants to be.
A day in life for Ruqayyah often includes homework for her college courses, working at Schnucks, and relaxing while watching her favorite TV shows. Highlighting her dedication to independence, Ruqayyah stated, “I figure out how to get to work” when asked about her daily routine and how she was able to navigate her community. She also stated that she loves being an active advocate in her community, particularly for people with disabilities. Paraquad also introduced Ruqayyah to Coalition for Truth in Independence (CTI), which led her to co-teach sexual education courses with Planned Parenthood.

To this day, Ruqayyah is incredibly grateful to Paraquad for the relationships she has fostered through their programs, as well as the opportunities she was able to pursue with their support. She hopes to see a change in the way people with disabilities are treated, especially regarding education about disability rights:

“I just want people to know that people with disabilities need to be educated like everybody else; don’t treat us any different...If you do, we aren’t going to learn... A lot of people with disabilities are misinformed and then we believe that everything is right, and I don’t like that I have been misinformed.”

In response to the question of what independent living meant to her, Ruqayyah stated it was important for her to, “...continue being as independent as possible and learning to become more independent every day you wake up... no matter disability or not because we all have to learn everything in life.”
Josh’s Story

Joshua Lewis was born with a broken neck that resulted in paralysis. Doctors at the hospital initially recommended his parents place him in a home, thinking that his disability would prevent him from living a fulfilling life. Joshua’s parents disagreed with this belief and chose to take their son home and raise him. Max and Colleen Starkloff, founders of Paraquad, visited Joshua’s home and encouraged his parents to treat him as they would any other child and to not limit him because of his disability. Joshua blossomed with this mindset. He moved out of Special School District into public school and later attended Westminster College for his undergraduate degree. As one of the first students to use a wheelchair, Joshua worked with his school administration to add ramps and other modifications that made the campus more usable for individuals with mobility devices. Later, Josh also received his Master’s in Legal Studies from Webster University, started a private investigator business, taught college-level content online, and became a fierce advocate for Universal Design. Joshua has contributed to multiple organizations as an advocate for disability rights and Universal Design, including a position at the ACLU of Eastern Missouri. He is currently working on a Universal Design ordinance for St. Louis County.

Joshua has utilized Medicaid throughout his life and finds it to be a valuable and necessary resource. However, he notes that it is difficult to navigate. Critics of Medicaid often seek to reform the program, citing potential fraud as a leading concern. However, measures to prevent fraud often make resources more difficult to acquire for those who need it. Paraquad has played a significant role in Joshua’s life since birth. Max and Colleen provided initial support to his parents in learning how to raise him to be independent and involved in his community. He also attributes his success in college to Paraquad’s services. His involvement in Paraquad has now evolved into a partnership of sorts, as he uses their supports and knowledge to inform and guide him in his Universal Design activism.
Edna’s Story

“I would’ve grieved myself to death”

Those were the words uttered by Edna when she thought about what life would be like inside a home if Consumer Directed Services (CDS) were unavailable to her. Edna, a 90-year-old, 2-time cancer survivor who enjoys drawing, coloring, and making jewelry took the time to share with us how grateful she is for everything CDS has provided for her the past 13 years and stated that Paraquad, the organization that set her up with CDS, is one in a million. Her experience with Paraquad and CDS has given her hope and she knows that she can always depend on them to help her and others.

Edna grew up in the Presbyterian church and has multiple siblings, children, and grandchildren. She started using Medicare/Medicaid in 1994 when she got sick and has since suffered a minor stroke, defeated cancer twice, and experiences vertigo. One of her daughters had to quit her second job to take care of her mother, which is when they learned about Paraquad and CDS. Now, her daughters are currently employed as CDS providers and take turns helping their mother with things such as getting around and helping her to the restroom. Because of the low-wage CDS providers receive, Edna tries to help her daughters as much as she can.

As a firm believer in Paraquad and CDS, she states that she is sure they help people live longer, better lives. She’s never had a bad caregiver and knows that Paraquad truly cares about the recipients of CDS as they send out monthly surveys to get feedback. Edna stated that she would not change anything about the services she receives through Paraquad and CDS and she is forever thankful for them.
Willie’s Story

“CDS are a way of feeling like you have a home, your own home”

This is how Willie described the services Consumer Directed Services (CDS) provides for him. Without them, he believes he would be shoved in a corner in some nursing home or institution and be made to feel like a sheep. Willie, who lost his eyesight and suffered a stroke, has been using CDS since 2013 and says their services have provided him with peace of mind.

For Willie, he believes Paraquad and CDS are a godsend. As a homebody, he prefers to live in his own home and be able to participate in the activities of his choosing, without worrying about a roommate. CDS has allowed him to live independently and maintain skills that he still has, rather than be in an institution where he would feel locked away.

He knows that Paraquad and CDS truly care for him and support him. They help him with finding resources, living spaces, or can connect him with someone who can help if they are unable. They keep him up to date on legislation, upcoming elections, and ensure that he feels his voice is heard.

Though grateful for everything CDS has provided for him, he noted how overworked CDS providers seem due to a cut in caseworkers. He knows they are not adequately compensated for the work they do and how the participants seem to lose hours, even though they are needed. He wishes there were more caseworkers and a living wage for providers because he knows how important they are to ensuring people have the choice to live independently and be active participants in their communities. In addition, Willie stated that when Medicaid decisions are made, program administrators don’t necessarily take into account personal perspectives of the recipient and he wishes there were more personal choices involved.

We are so thankful to Willie for taking the time to share his story of using CDS with us. The impact these services have had on his life emphasized the importance of their role in people’s lives.
Debra’s Story

Debra spoke to our group with a lot of passion for the work of Paraquad and the impact that Consumer Directed Services has had on her life. She described her life more than 10 years ago before receiving services, when she had such little accessibility to be a part of the community and appreciate the value of her life. She spoke about the gift of living more independently and recreating her social life, which all allowed her to “Enjoy life again.”

Debra said that Paraquad has impacted almost every aspect of her life, as they are consistently in communication with her. She also spoke to the value of their communication as allowing her to have a broader understanding of the policies for Consumer Directed Services as well as the general climate of the City of St. Louis, especially during a pandemic. The ability to enter and hear about the community that is important to her has led to her feeling a lot less isolated and like a part of something bigger than herself.

These resources have been so impactful on her life that she spoke about how she advocates for her peers to reach out to Paraquad and see if they might be eligible for CDS, as it has allowed for her to live a more meaningful and focused life. She spoke about her hope that the government will work to increase the provider rate for those who utilize Consumer Directed Services. She also was hopeful that she and others may be eligible to receive more hours of support from those providers so that she can get all the support she needs to be as successful as possible.

Debra talked about the services provided by CDS and Paraquad in an incredibly positive way. She continuously spoke to the life-changing impact these supports have had on her life over the last ten years.
Serina’s Story

Serina is a strong woman who has benefited from the Consumer Directed Services (CDS) by giving her a community to be a part of and the courage to transfer out of an abusive relationship. Before finding out about Paraquad and CDS, Serina was in an abusive relationship; she did not think she would be able to survive if she left. After applying to CDS, she was able to transition and Paraquad gave her the support and strength to continue without her abusive partner. She was given the impression that she was nothing, but Paraquad has allowed her to have control over her life.

Serina is a 32-year-old woman with four children, who was born with a mutation. She enjoys writing, poetry, and creating jewelry. She has been a part of CDS for the past five years. Lack of care and support can push people towards street drugs or excessive alcohol. She stated that CDS gives people the support to stay alive longer because it directs them away from harmful substances and towards healthier occupations.

When asked what the challenges CDS have, Serina pointed out how intimate the program is. Even though Paraquad does a good job at making its consumers comfortable, it can still be difficult having people enter their homes to help with their daily tasks. CDS also has a lot of restrictions about who can come into the program, and the questions themselves are also extremely personal. Even though Serina did not feel ashamed about answering these questions, she empathizes with others who might have difficulty sharing. Personal questions, such as ‘can you use the restroom independently’ and ‘how much cash do you have’ should not be the reason that people do not receive services.

Serina also wanted to encourage others who are going through a hard time that even though there are hurdles to jump, when you reach the other side and receive help, it will all be worth it. It makes a difference to receive help.
A SPECIAL THANK’S TO

SAINT LOUIS UNIVERSITY
OCCUPATIONAL THERAPY STUDENTS

WASHINGTON UNIVERSITY
OCCUPATIONAL THERAPY STUDENTS