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Capstones

Craig Newmark Graduate School of Journalism

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Using Engagement Journalism to Serve the Needs of Caregivers of People with Autism

Ariam Alula

Craig Newmark Graduate School of Journalism

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I'm Ariam. I worked with a diverse group of families who are intimately impacted by the autism spectrum disorder and other disabilities through caring for a loved one with the diagnosis. During the program, I used my journalism education, advocacy work, and interpersonal skills to support the emotional and informational needs of the community. The majority of the caretakers I engaged over the duration of the program reside in the Bronx, my home borough. I chose to focus on the lived experiences of people in this community because they represent my own. I have an older brother on the spectrum who lives with me and my family in the Bronx, and I've witnessed my parents live under high levels of stress over the years and throughout my adolescence and I have seen the manifestations of that stress (weight gain, sleep deprivation, high blood pressure, etc.) I used a community engagement event, 360-degree storytelling, a personal essay and stories to amplify the voices of older and younger caregivers.

They aren't the only ones.

Forty-two percent of adults who care for at least one person said they want information about managing their own stress in a 2015 report by AARP's "[Caregiving in the U.S.](#)" Another survey produced in February 2019 by The Arc and the National Center for Children in Poverty's [Disability Perspectives on Paid Leave](#) interviewed caregivers in New York, New Jersey, North Carolina and California about their perspectives on the paid family leave benefit which, by law, allows employees in these states to take time off work, receive a percentage of their salary, and still keep their job in order to take care of a family member or their own health. Sixty-two percent of the caregivers (90 percent identify as parent caregivers) said they have taken a leave of absence for "a few days" to take care of a sick or disabled family member compared to only 25 percent who said they have taken a few days off work to tend to their own needs.

Stress is a part of everyone's lives but stress for caregivers can become tenfold. My goal was to engage this community by producing at least three wellness events for them to learn how to manage their stress using different techniques. However, due to the scheduling of support groups and time constraints for my partner for the project, I was able to produce and co-create one community engagement event with 13 caregivers on Monday, November 18. I partnered with a caregiver who I have known for almost two years to make this vision a reality. Her name is Dru and we had carefully crafted this date and our agenda to accommodate the needs of other people in the community. We were partners for this project and remained in close contact since my Spring semester at Newmark J-School.

In thinking about how we might make the practice of meditation accessible to caregivers, I also produced and showed this 360-degree video to caregivers at the workshop to generate a conversation about stress management. I took everything I needed including VR cardboard headsets and headphones to make sure caregivers had the proper equipment. But I forgot to bring

an adaptor to connect my laptop to the flat screen television in the room where we held the event. I had asked about the projector and communicated my technical needs prior to the event, so I felt disappointed to learn at the eleventh hour that I couldn't show my video on the flat screen.

My practicum proposal as of mid September

Wellness Events	Aligning with my community vision, <i>I will produce at least three educational and social events for caregivers to release stress</i> through (meditation, yoga, tapping or the Emotional Freedom Technique, walking in nature, etc.) and provide accurate information about stress management for caregivers.	This goal is to fulfill an emotional need for caregivers to learn how to manage their stress, connect with each other, and ideally reduces feelings of isolation.
Partnerships + Facilitation	I will get <i>buy-in from stakeholders</i> in the community by collaborating with at least three different caregivers and organizations (including teachers/social workers) to host these events.	This goal will help me see the thread amongst a vast network of people who live in different places but are all connected by autism. I also believe building partnerships will help me continue this work beyond graduate school.
Data-Driven Report	I will <i>develop (sources, structure, etc.) and publish a story about access to services</i> for the autism population in multicultural Queens.	This goal will bring awareness to issues around access to quality services among non-native English speaking communities in New York City.

What actually happened (as of early December)

Wellness Event	Aligning with my community vision, <i>I produced one event</i>	This goal helped me fulfill an emotional need for caregivers
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	<p>for 13 caregivers to help them release stress through meditation and mindfulness. I also presented information about local and national research pertaining to stress management for people in this community.</p>	<p>to learn how to manage their stress in a supportive environment with other caregivers.</p>
Partnerships + Facilitation	<p>I received <i>buy-in</i> from Tina Veale, the chair of the Bronx Family Advisory Support Council, who allowed Dru and I to host an hour-long workshop after the group's November 18 meeting.</p> <p>The Asperger's Autism Network also welcomed me as one of two adult siblings facilitators for their online teen support group for siblings of people that meets once a month for an hour. I participated on October 16 and November 12.</p>	<p>This goal will help me see the thread amongst a vast network of people who live in different places but are all connected by autism. I also believe building partnerships will help me continue this work beyond graduate school.</p>
Experimental Content	<p>I shot, edited and produced a 2 and a half minute 360 video showing a day in the life of Dru Ramdin, a caregiver in the Bronx who was a stay-at-home mom for the first 15 years of her son's life. I showed the video to caregivers at the workshop in the Bronx on November 18.</p>	<p>The goal of inviting caregivers to watch the video (as part of one of my presentation slides) was to generate a conversation around their mental health.</p>

B)Background and context. What you learned about your community and its needs, and especially how you know. Establish your expertise. You don't need footnotes but you should link to your previous work or other content that may be relevant and carefully attribute facts. It would be nice to see quotes from community members or data you've collected to help establish this.

Community Needs

Stigma

Caregivers don't always feel empowered to discuss their child's diagnosis in public or within intimate social circles. Earlier in my project, I talked to about 8 to 10 mothers about stigma. Additionally, I included a blog link from Kpana Kpoto who is a family educator who works for INCLUDEnyc. [INCLUDEnyc](#) is a nonprofit organization serving families of people with disabilities through educational and recreational programs. I attended one of their well known workshops -- Understanding Your Child's IEP -- in October of last year to listen to the community as well as fulfill the [non-participatory observation assignment](#). I have not worked with INCLUDEnyc yet but I plan to approach the organization this semester and ask for their help to spread the word about a wellness event.

Adhanet Zereabruk	“Everything in our culture is taboo. [Families] think if they talk about their child’s disability out in the open people will judge them.”
Leah Seyoum	“You want help from me but you don't even tell me your kid has autism. That’s stigma. It’s heavy on us, unfortunately,” said Seyoum about her decision to reject a parent from joining a Facebook group meant to support parents of children with disabilities. Read more about the role that stigma plays in the community here .
Kpana Kpoto	“The stigma of disabilities like autism is real. This is part of the reason why I am very passionate about the <i>love, equity, and access</i> that INCLUDEnyc seeks to promote for people with disabilities.”

	Read more here .
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Stress/burnout

Caregivers experience high levels of stress due to life responsibilities such as work, school, relationships, etc. But those stressors become tenfold when caring for a person with greater needs. Here is what one mother in the Bronx said about parenting a child with a disability in this audio [slideshow](#).

Dru Ramdin	“With Fabian sometimes you have to be his hands, his feet, his eyes, his ears, his mouth.”
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Access to quality services

Caregivers aren’t always aware of the services available to their family members. In some cases, they just aren’t happy with them. A sibling from Queens spoke to this issue last semester. A brief phone/text conversation between myself and a single parent named Yvette Parish (“Vette” for short) also alludes to the anxiety caregivers experience when enrolling their loved ones into new services.

Jasmine Ferrer	“It’s frustrating trying to navigate the system. Services don’t always fit my brother’s personality or his interests.”
Vette	<p>“My baby’s leavin’ me in a few weeks. His [care coordinator] found him a camp. It’ll be his first year. Mama needs to rest.”</p> <p>Weeks later via text: “Gd morning my big pj is off to camp I miss him already” (teary eyed emoji)</p> <p>Note: PJ is 18 years old. He is Vette’s youngest son.</p>

Parental concerns around guilt, coping mechanisms for younger family members and providing ways for ALL children to bond

A few parents from the Reach DFW Families and Beyond network who were on the conference call that evening spoke to these concerns during Q&A. Reach DFW Families and Beyond is a network of East African families of people with disabilities that host monthly conference calls with professionals (people who have specialized knowledge on a topic) and meetups in person. I have spoken to the group administrator Leah Seyoum, a mother and case manager who lives in Dallas, online and over the phone. I’m a member of this closed Facebook group and closely observed them for a few weeks during my first semester in social-j. More on that listening experience [here](#).

Parent 1: Did not get name	<p>“I have an 11 and 9-year-old. They get uptight and struggle to have people over our house.”</p> <p>The parent then asks me: How were you able to connect with your brother when you were younger?</p>
Parent 2: Elsa	<p>“I feel guilty because I feel like my attention is toward [my son] and not her. She has said ‘Mom you don’t pay attention to me, sometimes it’s about my brother.’ My daughter is 10; she already has anger and resentment.”</p>

Lack of education about special ed services \ IEP process

Include NYC hosts weekly workshops tailored to the IEP, or Individual Education Plan, process. I attended one of the workshops at a public school in Brooklyn to meet and connect with families who would normally be out of reach. (At the time I was only focused on families in the Bronx.) So I connected with LaTasha Green who is a Parent Coordinator at P4K in Kings County which serves over 300 students across seven schools. She spoke about stigma as well as parent’s lack of education about the IEP process.

Latasha Green, 15 years of experience in	Said parents ask these questions the most:
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King's County school system	<ol style="list-style-type: none"> 1. What changes can I make to my child's IEP to request speech? 2. What changes can I make to my child's IEP so that my child can ride on a smaller bus?
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Data about the Community

I accessed national and local research about caregiver's health concerns.

<p>Caregiving in the U.S. by National Caregiving Alliance focuses on the informational needs of caregivers</p>	<p>Caregivers in this study of 1,200 plus participants categorized caregivers in three baskets: high burden, medium burden and low burden. This classification is based on the number of years an individual has cared for another person. The first group has given care for 4.8 years. The second group has given care for 3.2 years and caregivers who consider their job a low burden have been in the role for 3.5 years. caregivers)</p>	<p>Caregivers want information as outlined in page 63 of this report:</p> <ul style="list-style-type: none"> - Keep care recipient safe at home - Managing emotional/physical stress - Making end-of-life decisions - Managing his/her challenging behaviors - Managing his/her incontinence/toileting problems - Finding 	<p>I've used this statistic in my work with the community (Medium post, workshop):</p> <p>Forty-two percent of caregivers who devote more than 20 hours of caregiving a week said they would like more information about how to manage their own emotional and physical stress.</p>
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		non-English language educational materials	
<p>Disabilities Perspectives on Paid Leave: A Qualitative Analysis of Leave Taking by People Affected by Disabilities or Series Health Concerns by The Arc and National Center for Children in Poverty</p>	<p>Caregivers in this survey of 90 participants from New Jersey, New York, North Carolina and California identified as someone who had a disability or serious health condition and/or have experience being the primary caregiver for a friend or family member with a disability or health concern. The report also has sectioned recommendations for policy makers, employers and advocates.</p>	<p>Survey participants expressed a few of their concerns about disclosing that they or their dependent had a disability such as stigma and fear of losing their job.</p>	<p>I have used this statistic when working with the community:</p> <p>Sixty-two percent of participants said they took a few days off from work to provide support for a family member or friend, compared to 17 percent who took time off work to address their own health.</p>
<p>Int # 1236-2016 New York City Council bill</p>	<p>Various city agencies including New York City’s Department of Mental Health, Developmental Disability, Alcoholism, and Substance Abuse created a bill that would require the Department of</p>	<p>I had discovered flaws in the annual report based on the data set. The report looks at individuals on the autism spectrum between 3 to 25 years of age, which doesn’t include individuals outside of this demographic. I</p>	<p>I have used information from this graphic when interviewing caregivers for a data story in May 2019.</p>

	<p>Mental Health and Hygiene to report on the incidences of people with autism and make that information available on its website. One of the attachments linked to the 2017 annual report on the number of individuals receiving services for an autism spectrum disorder.</p>	<p>also suspect more than 4,000 individuals in NYC have autism. What fascinated me the most was the discrepancy of services among the individuals who live across the boroughs. Individuals in Brooklyn received a greater number of services than residents in Staten Island.</p>	
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Tell us what you did for your practicum. Include as many links as possible and any relevant details. This is pretty straightforward - you are reporting back on what you've done. Remember to include context as needed. Don't just tell us, show us with clear examples and quotes. Feel free to use subheads for each of your different initiatives or projects. If you have published pieces in any media format, please include links!

Meditation for the Caregiver

I co-hosted the first in what will hopefully be a series of wellness workshops with 13 attendees at the Bronx Family Support Advisory Council meeting on Monday, November 18 from 12 to 1 p.m at the Bronx Developmental Disabilities Office. Our workshop titled Meditation for the Caregiver was inspired by the "[You Are Here](#)" engagement model, which aims to thicken the relationships among community members who have a shared concern.

Dru and myself decided to reach caregivers where they normally are on an early Monday afternoon and build on the relationships and shared experiences that exist within that space. I centered my presentation around who I am, the conversations I've been involved in for the past year and change, and highlighted national and local research on stress and the caregiving community to surface a conversation around their mental health. I also played the 360 video of Dru who recounts a time where meditation helped me navigate a stressful situation with professionals at her son's school. People were willing to share what they do to destress and how

one person reiterated that “looking calm” doesn’t mean you aren’t experiencing stress. Dru took the second half of the workshop by leading caregivers through a guided meditation. We flicked off a few lights to set the mood.

Here is the link to my [presentation slides](#).

You can listen to a snippet of [Dru’s guided meditation](#) here. Please note that the sound cuts off after 1 min.

Metrics, outcomes and impact. Using what you learned in the metrics and outcomes course and in other courses, describe the impact of your work on your community using as many measures as possible/relevant, both quantitative and qualitative. To give this section of the report structure, assemble metrics around your various "channels" or “entry points” of engagement with your community e.g. websites, articles, events, face-to-face gatherings, surveys, etc. You should include quotes/comments from your community speaking to your impact and their evaluation of your work.

1. Meditation for the Caregiver

- [Web Page](#)

Attendance: 14 (One left early and did not fill out a survey)

Women: 12

Men: 1

- One anonymous survey (person didn’t write his/her name)

How many people were parents? 11

Nine people said they are “very likely” to recommend our workshop to another friend

I collected 13 [surveys](#). Results show.

- Nine people rated our workshop a “9 or a 10” which means they are very likely to recommend this workshop to another caregiver (two people gave it a 9)
- Three people rated our workshop a “7 or 8” which means they are likely to recommend this workshop to another caregiver
- On average people said they felt a calmness of 7 compared to how they felt at the beginning of the workshop
- Two people circled “yes” and said they would like to participate in a diary self-study with me
- Five people circled “maybe” about participating in a diary self-study with me
- One parent was moved to tears. Said Dru’s meditation “took her back” to a trip she took to Mexico six or seven years ago.

- Another person said she likes to “draw water into a bath and just sink in it like a tube.” Also mentioned going shopping and window shopping as other ways to unwind.
- One mom said she remembers attending an event on releasing stress years ago that compelled her to take two months off work.

After two to three weeks of the workshop, I called and asked them these [questions](#). A few picked up. Some couldn’t talk at the moment. Here’s what they said.

2. [Shh, Don’t Tell Anyone My Son Has Autism](#)

Views: 726

Likes/claps: 216

Read Ratio: 30%

Comments:

This screenshot is of a text message sent by a friend who shared my piece in a group with other black school psychologists.



From Hayat O Hussen: "Ariam Alula i have been told shhhhh dont say anything too. Our community need to learn its ok to talk. I talk about my son strengths what accomplished after going his Therapy . The benifits of Early intervention. We dont need to be shhh.Talk about it. Thank you again. I hope everyone in Habesha community read this.



From Adhanet Zereabruk who was interviewed for the story: “Hey Ariam how is it going? Sorry I have been MIA. My family and I moved to Atlanta back on April and we have been working on adjustments and DIY projects on our house. I hope all is well with you and your work. I just read your article now and I am proud of you and what you have done with the information you received. You really did your homework and did an amazing job. You are an amazing gift to our community and I feel it in my spirit that God is going to use you in bigger ways. Let's

keep connected.

3. [Queens Residents Contemplate Access to Disparities in Services](#)

Views: 12

Likes/claps: 7

Comments:

4. [I worry about how to take care for brother with autism and his mental health when my parents are gone](#)

I'm still working to get metrics for this essay from the editor at The Black Youth Project, however, here are a few comments posted by other siblings on facebook.

BLACKYOUTHPROJECT.COM

I worry about how to care for my brother with autism and his mental health when my parents are gone - The Black Youth

Olivia Haller, Liz Richards Krebs and 24 others 10 comments

Like Comment

Pamela Lowy Layne Thank you for sharing this, Ariam. Beautifully written, and expressing concerns we all have. Love to you & your family.
Love · Reply · 30w 1

Courtney Graff 🗨️ I worry about this too. My parents I think just automatically assume that all 3 of my siblings will come and live with me and my husband and 2 children when they can no longer take care of them; they joke about it around other people all the time in pu... [See more](#)
Like · Reply · 30w
↳ Courtney Graff replied · 4 replies

Lindsay Congleton Greco 🗨️ Excellent work! ...
Love · Reply · 30w 1
↳ Ariam Alula replied · 1 reply

Prema Polit Thank you for writing this! It's so hard to have these conversations and get our parents to think about things that scare them.
Love · Reply · 30w 1
↳ Ariam Alula replied · 1 reply

Reshared by the administrator for the Reach DFW Families and Beyond on May 23



Leah Seyoum-Tesfa

Admin · 23 May

Please read !!Parents!!! Especially parents of older children with siblings. We need to have open family discussion with the all our children/ sibling about the future. The reality is most of our children will out live us. Siblings are going to be carrying the burden and we need to share information and our hopes and wishes on how they will be cared for. Thank you Ariam Alula!!

<http://blackyouthproject.com/i-worry-about-how-to-care-for.../>

My essay was also featured in the Sibling Leadership Network on July 8 newsletter + [website](#). The Sibling Leadership Network is a nationally recognized nonprofit that supports the informational needs of siblings of people with disabilities.

The Diaspora Dialogue

My passion, bridge-building project is about bringing communities who have traditionally been at odds together to talk about a way forward - one conversation at a time.

I facilitated a three-hour community conversation about the cultural and historical dynamics between five Eritreans and Ethiopians on Wednesday, December 5 at the radio station of the Newmark J-School. A lot of superb themes emerged including, but not limited to migration, war, interracial dating and marriage, colorism and parental expectations. I edited a few soundbites from each participant and posted it on Soundcloud for people to get a taste of the conversation. I will edit the conversation into shorter segments based on one of the themes previously mentioned and transcribe it for listeners.

To help me facilitate the conversation, I printed out individual copies of the [agenda](#) for the participants. We didn't get to go through each prompt, but heavy and juicy themes emerged from our conversation including migration, war, interracial dating and marriage, colorism and parental expectations. I edited a few soundbites from each participant and posted it on [Soundcloud](#) for people to get a taste of the tension, joy, and heartache poured from the participants as they told their stories.

This project took months in the making — from meeting with studio managers in outer boroughs and even attempting to leverage my own connections with BronxNet from my three-month summer internship to scouting potential guests in person and on social media to crafting an agenda that encourages dialogue that emphasizes personal experiences over opinions — I felt victorious and proud to have brought this conversation to life.

My idea to facilitate this conversation came from the multiple sources that I had researched and referenced over the better part of the year. One, in particular, came from Spaceship Media, a

journalism startup that seeks to produce civil, meaningful interactions online, was an organization that I had learned about while speaking with Class of 2017 Social-J alums [Alyxaundria Sanford](#) and Kristine Villanueva. They were moderators of The Many which was a nine-month project that brought voters from different sides of the political spectrum to discuss their questions, concerns, and hopes for the future of American society and politics in 2018. The startup published a [toolkit](#) explaining their Dialogue Journalism platform which highlighted this takeaway from Sanford, “As the group grew and time went on, I saw members change their approach, take time before reacting to comments, and openly admitting they had never thought of things they way someone may have presented them.” As the moderator for the Diaspora Dialogue, I heard feedback from participants that reflected the immediate impact this sitdown had on them.

“I came here to learn something and I did. It was interesting to hear what others had to say about our cultures, said Miriam Negasi, a 20-something-year-old school psychologist of Eritrean heritage from West Orange, New Jersey, who had expressed her initial discomfort upon hearing an Ethiopian-American millennial say that her country and Miriam’s homeland were “the same.”

My plan is to edit the conversation into 10-minute podcasts based on themes previously mentioned and create a facilitation guide for other Eritrean, Ethiopian and African communities globally to conduct conversations in their respective cities.

A)What did you learn through this process? What went well?

Big ideas can happen anytime and anywhere, and mine usually emerged out of conversations. During a phone interview with a mother in Brooklyn, the idea of having a podcast arose at the end of a 55-minute minute. The mother said she wanted to invite me to her show, a series of living room conversations with her and friends at a studio in Queens. I jumped on the idea but in the coming weeks she was slow to respond. So I moved on from the idea with her and continued on with life as is. I eventually met another mother while at a training in Long Island in late November. She gave me a book to read; it was one that she had written and used in conversations with grade school students to enhance their understanding of autism. I thought about inviting her to the school to record a podcast with me in the radio station; turns out she loved the idea. She wasn’t the first mother from Long Island that I wanted to interview that month; she was the third one, but this time it worked out in my favor. This experience reinforced my understanding of how ideas sometimes work out. We may have great ones but would benefit from patience and compassion to ourselves and others if we want to see them come to fruition.

I also learned that journalism is better when we, as journalists, shift our thinking of sources as collaborators. Dru was an older caregiver I met at a series of behavior management workshops between January and March 2018. We learned about each other’s family dynamics; she was the matriarch of her family, I was the know-it-all, overachiever child of mine and overtime we developed a mutual respect and understanding of how the other lived. We had kept in touch

periodically every few months and later that year, I joined the Social Journalism program which she was excited to hear about. Little did I know, Dru had been going through a transitional phase. After 15 years of being a stay-at-home mom and full-time caregiver to Fabian, her son, Dru began taking classes at an accelerated nursing program in Manhattan. So our conversations naturally swayed to our mental health, how we were managing family responsibilities in this new role, and so forth. Soon the idea of creating a workshop for caregivers to help them manage their stress bubbled up again. Our first attempt at bringing caregivers together for a two-hour meditation workshop in the Community Room at Parkchester Library saw only one person walk through the door to be with us for 60 minutes. We knew the low turnout and extra time wasn't what we had in mind for impacting other caregivers, but we felt good about starting at the very least. Through this process of iterating our workshop, I learned to always have the community's input a part of whatever it is that's being created. Doing journalism with communities and not for them is at the essence of Social Journalism's philosophy and I'm grateful to have seen the fruits of our efforts come to life this Fall.

What are you most proud of?

Empowering people who care for others to care for themselves was at the heart of my collaborative relationship with Dru, which led to trust and committed action of both of our ends.

Dru and I had passed out copies of this flyer to agencies that were connected to families of people with disabilities on Sunday, October 13 at the Disabilities Expo in the North Bronx neighborhood of Coop City. A friend of Dru's who is also a caregiver invited us. Dru talked about the importance of our workshop to a room full of 8-9 community stakeholders and I passed around copies of flyer at the time. A few people had taken our flyers home with them, but ultimately the group we'd decide to serve was already formed. It was a group of parent caregivers and one self-advocate led by Tina Veale, a long-time advocate of the disability community in the Bronx, who had invited us to give the same pitch at her October 21st meeting at the Bronx Developmental Disability Office. That following week, Dru and I decided it was best for me to pitch our workshop to these group of caregivers. Dru couldn't make that meeting because of class responsibilities, however, I reported back everything the caregivers had expressed to me and we were set to go for the November 21 workshop. I'm most proud of the way we communicated with each other about our intentions and the strengths we could bring to the community while planning our first (well, really second) workshop to caregivers. We didn't use a nonprofit or ask for funds to make this workshop possible for people in the community. All we relied on is connections, word of mouth, a few online resources that I had created (a few versions of our flyer and a web page) and the rest unfolded on its own.

I'm also grateful for my ability to push forward with publishing content that initially concerned me as in the example of my first 360 video showing Dru in her home on a quiet weekend. The

premise of the video is to show a caregiver in some of her most private intimate moments with a care recipient. Dru's son, Fabian, had just gotten back from a long day of fishing at Randall's Island and he was pretty wiped by the time I arrived at their home in Castle Hill. I questioned how compelling the footage would be to the viewer watching it. That said, I tried to find ways to get Dru to talk about her caregiving role and even showed her tidying up Fabian's workstation and pushing him in their living room hammock. Our interview also went very well and felt natural which is a result of our history as collaborators. Despite my initial concerns the video turned out well and it will be shared on a platform called [The Caregiver Space](#) on February 11.

What might you do differently if you had to do it all over again?

- The idea of reaching caregivers to invite them to workshops became more manageable once I connected with a support group in the Bronx where caregivers already meet once a month. I did this in October at the Bronx Family Support Advisory Council meeting, however, I believe I would have been able to produce more events with the community had I been able to focus my efforts on one group. During the summer we tried doing it on our own (by inviting caregivers we knew in the borough to come to us) and only one person showed up. We had interest from a few caregivers but seeing my efforts to secure a place (Community Room at the Parkchester Library) and Dru's efforts to dazzle up the space (candles, table cloth, water, etc. to set the scene) detracted us from outreach which also didn't help in the end.
- From my experience, the few men that I've interacted with were the husbands or partners of women. I suspect this has to do with work obligations and once heard a caregiver say in passing during a conversation "men don't always stay around when these things happen". Male caregivers are less visible in this population and all along, I knew that not having a male caregiver perspective in my stories and conversations was a disadvantage. If I had to do this program all over again, I would make explicit requests of organizations like the Sibling Leadership Network, AHRC, YAI and Reach DFW Families and Beyond to be connected with the men of this community.

What challenges did you face and how did you overcome them?

- Our [Dru and mine] efforts to promote a conversation around mental health among caregivers fell short until we went back to the drawing board and figured a way to do this with the community's input. We went from having only one person show up at our July 29th workshop to standing in front of a room of 14 people (one did not identify as a caregiver) after just four weeks of planning an event. We had developed our credibility as

trustworthy caregivers because our connection to Tina Veale (another caregiver) and because I had shown up at a meeting prior to our November 18th event to talk about our intention behind Mediation for the Caregiver.

- I placed a lot of pressure on myself to produce another event with another community I belong to -- the Eritrean community. As a friendly text conversation began to go awry, I came up with the idea of hosting a forum where Eritreans and Ethiopians can talk about their differences and similarities in a civil yet honest conversation. The friend who I had an argument with via text is from Ethiopia and migrated to New York City over the last decade. My parents made a similar journey in a very different time during Eritrea's 30-year war for independence or armed struggle (1961-1991) to New York in the mid-80s and I learned a lot about our country's history *through their perspective*. I wanted to explore a conversation about our nation's histories and differences with people of Ethiopian descent, though I initially had concerns. Who would moderate the conversation to make sure everyone's voice is heard? Would I be fit for the job - I'm Eritrean, wouldn't that look biased to people who listen to our conversation? I had all these questions and leaned on advice from different friends. Once I began to compile a series of prompts, I started recruiting everyone who I knew that lived in the NY Metro Area who would be interested in participating. I thought of the same friend who I had the upset with and he didn't seem too jazzed about participating. I had another friend, also Eritrean, who records a podcast in a studio in a bordering Brooklyn and Queens neighborhood. I visited the place and it took a total of 2.5 hours to commute to the studio from the Bronx. Next, I knocked on BronxNet's door where I had done my internship over the past summer. They were excited for the opportunity to host our community conversation but ghosted me twice over a period of two months. We'd start a conversation and then I couldn't get a hold of anyone due to their staff availability, preparation for their 25th anniversary, holidays and time conflicts with the availability of my guests. I was fed up with waiting and took the matter into my own hands. Finally, after about four months of iterations I invited a small group of guests to the radio station at Newmark J-School to discuss the dynamics of our community for 90 minutes. The conversation lasted for about three hours with one 15-minute intermission. I overcome the challenge of finding the "right" space and the "right" time to host The Diaspora Dialogue by starting over and starting small. I go to a journalism school, I thought. Why not use the space in the studio? And, after a while, it became clear to me that I was the best person to facilitate/moderate the conversation because I had a personal relationship with most of the guests and spoke to everyone about their intentions/why they wanted to participate in the first place. Listen to this 35-second [teaser](#) from the conversation. An edited and transcribed podcast will be posted in early 2020.

B)What are *most critical* insights you have developed into the practice of social journalism as it applies to your community? How might you distill a handful (3 to 5) of best practices for engaging this community (and tell us how you know this)?

I discovered a UK non-profit communications organization called [On Our Radar](#) which facilitates and promotes media, research and advocacy projects between unheard and influential voices around the world. I learned about the agency on the Engaged Journalism Accelerator database and dug around to find their [manifesto for journalism](#) published on Medium in early November. Here are a few that resonates the most with my experience doing social journalism with my community.

- **Professional skills and lived experiences are a powerful mix**

Bottom line: I don't know how far I would have gone in reaching caregivers outside on my family's network without telling my own story and making the initiative to connect with people despite our shared experience of disability. Earlier in the program, I began working contacts with people I already knew which included the people on my spreadsheet Daniel's Community. But that connection prior to graduate school didn't always pan out in deeper connections or collaborations. For example, I knew that Dru wanted to do something with stress management and she worked with me throughout the year on other projects including an audio slideshow that I produced in Meredith Bennet-Smith's class until she felt she was ready to start talking about meditating with other caregivers. This involved patience on my end and explaining how the kind of journalism I'm studying and doing in real life can be a part of the meditation event. There was another mom from the same workshop series that Dru and I had met in early 2018 that would sometimes answer my calls, when I reached out to her during the course of the program. She would ask about my sibling (goes back to our shared experience) but didn't seem to want to engage with me about school, my project and what else I was up to. I guess I learned that even though I came from a similar socio-economic background like many of these caregivers do I still educated people on what I was doing and why I was doing it. My professional skills as a journalist with empathy and lived experience as a caregiver was understood by most of the caregivers I worked with including the families I connected with on the closed, private Facebook group Reach DFW Families and Beyond. If I was just a journalist who didn't have a shared connection with these families, I would not have been able to listen to conversations that surfaced online and I think I would have had to explain myself as to why I had been showing up at community gatherings if I wasn't a sibling. Plus, I noticed many of the caregivers that I met opened up to me after I sent them a copy of No Plan for Daniel, now an award-winning piece that was published by the BlackYouthProject in May 2019.

- **People are the experts of their own lived experiences**

I am indebted to all the caregivers I worked with over these past 16 months because a lot of what I observed in their homes, from our conversations, in the content they had created (i.e. YouTube channel and a book) helped me learn about who they are and why it made sense to work with them. Take Amy Cobb, for example. We met at a sibshop facilitator training that lasted two days in Long Island and I casually asked if she could photograph me and a few other adult siblings during a panel on our upbringing, how we navigated family life as a sib, that sort of thing. I knew she was a parent because we (the trainers) had all introduced ourselves earlier that day and somehow we gradually began talking about her book and what she does. She quit her teaching job to be a stay-at-home mom and take care of her son, Matthew, who lives with autism. Ironically, she wrote a children's book from the perspective of her daughter who is two years younger than her brother Matthew. When she told me that she uses her book as a learning material to promote autism awareness among grade school student in her district, I knew I wanted to further explore that in a podcast together where we could create our own content as book lovers/storytellers and people who have a shared experience of disability. Nobody could have told me her story better than she did, which further proves the idea that people have the right to tell their own stories in whatever they want because it's their truth.

- **Better journalism happens when we see sources as collaborators**

My community engagement event would not have been possible without Dru's contribution. She connected me to Tina Veale, the chair of the Bronx Family Support Advisory Council, and throughout the process we talked about what would be discussed during my portion of the workshop and her portion of the workshop, what important was necessary to include on the flyer and we are still in talks about hosting future workshops.

- **Technology is a tool for listening not only broadcasting**

My advantage over other journalists comes from being a family member to a person on the spectrum, which means I have access to a private facebook group for other families who live across the diaspora. One group in particular, called [Reach Families DFW and Beyond](#), is comprised of mostly parent caregivers of children with special needs and was created in June 2015 out of a need to share information about resources for underrepresented families of East African origin in the Fort Worth area of Dallas, Texas. The group's administration Leah Seyoum has helped the group reached over 250 members spanning states across America, Europe and Africa. Seyoum also has twin boys on the spectrum. Some interesting files that have been posted in the group pertain to (1) toilet training, (2) nutritional dieting for individuals with autism, and (3) scholarships and

grants for families raising children with autism. The group hosts monthly calls too. Seyoum works with another mom in the group to coordinate speakers for the call. On average 30 families call in. “We had 72 people call at once,” she said in a phone interview on November 23, 2018. Seyoum posts the recordings online for families to listen to at their convenience. This past summer, Seyoum invited me to lead a conversation about sibling experiences and how parents can encourage stronger bonds between their neurotypical children and children with disabilities. Although I was accepted into this group because of my familial experiences, I still followed etiquette that all journalists would benefit from doing online as they would in real life like being transparent about who I am and engaging with community members, who have interesting opinions. I would spend 10-20 minutes every few weeks to stay plugged into conversations taking place in the community.

C) If you had to offer advice to someone who was just starting out in serving this community, what would you tell them? Apply lessons from all of your coursework as relevant.

I approached this program with ideas of what I wanted to write about. In hindsight, I realize I had made an assumption all along. Nothing is wrong about having an idea, but it’s just that I tend to stay in my head for a long time and doing engagement work with the caregiver community has shown me that knowing how to best serve a community comes from the community itself. My best advice for someone who is starting out is to read three new articles a day about people with disabilities and their families (a few reputable sources include The Mighty, Spectrum News, and The Caregiver Space) and talk to people who live with a disability and practice as much empathy while speaking with them. Don’t try to understand the community or what they want right away.

Disabilities look different on everyone and no two people with disabilities are the same.

Link to at least one piece of published or unpublished writing that you feel best showcases your reporting and newswriting skills. Briefly annotate this link with a short summary as well as a description of your process.

- I wrote a personal essay about coming to grips with the possibility that I may, someday, be my brother's sole caregiver.

Link to at least one piece of published or unpublished non-text multimedia you are particularly proud of... video, photo slideshow/series, podcast, etc.. Briefly annotate this link with a short summary and description of your process.

- [My Life in 360](#) centers on Dru Ramdin, a caregiver in the Bronx. In the video, we see Dru interacting with her son, Fabian but viewers don't hear from him because Fabian lives with autism. Dru briefly mentions a scenario where meditation helped me remain calm in a chaotic world. I developed this story through a five-week module with Matt MacVey at the Newmark Graduate School of Journalism. I shot scenes using a Ricoh Theta camera and its accompanying mobile app. I stitched the scenes on a software program and edited it in Adobe Premiere. I found an online community dedicated to caregivers called The Caregiver Space which will publish the video on February 11, 2020.
- Dru, a mother in the Bronx, talks about her life as a caregiver for Fabian, her 16-year son who lives with autism in this minute-and-thirty second audio [slideshow](#).

Link to a piece of your work in which you used data in some way. As above, annotate with a short summary and description of your process.

- [Queens residents contemplate disparities in access to autism services](#)
I discovered that residents in Queens had the second-highest number of services, after Brooklyn, but had the lowest average number of services for its residents for its population size. In other words, one in every 23 people in Queens received a service for their autism diagnosis. Barbara Gray and I had worked closely to retrieve this data set that showed the number of services for more than 4,000 individuals who live with autism in New York City. I worked with Malik Singleton, our professor for Data Skills, to configure the averages of each of the data sets. I connected with three caregivers about their experience navigating the system. Two out of three were from immigrant backgrounds and had speculated that the data set might reflect barriers to access for people of color who have a disability.

Link to the social media platform you feel you've been most successful at using to distribute your work and engage your community. Briefly annotate this link with a description of your approach to this platform and techniques you used.

❖ **Facebook groups**

- [Reach DFW and Beyond](#): I surfaced what types of conversations families were having about their children -- and was surprised by what I had learned. Parents of children with greater needs are similar to any other parent. They talk about a range of things from picking out the best food for children, traveling with their children, what sort of therapies were available for their children. Families had invited me to talk with them about sibling relationships after a few of the members had read my piece. Our call lasted two hours; I

talked about my relationship with my brother and my work as his advocate for the first hour and interacted with the parents through a Q&A for the second half. Here were some of their responses to my presentation:

- ❖ “I run a sibshop in West California, so [this] is an important subject for me. The sibling relationship is the longest and most important relationship that a sibling with a disability will have. We have to focus on this relationship. There are a lot of organizations supporting parents. Not so much on the sibling. It’s unfortunate. That needs to change.”
- “We are not only hiding our child’s diagnosis from the community, but we are also not talking about it with our other children. The conference was recorded, added to this group’s archive and can be listened to [here](#).



Live sibling chat via private [SibsNY](#) facebook group: In May, I hosted a conversation with me and three other siblings on the Facebook group SibsNY on Friday, May 10. I called the admin of SibsNY to ask if I could use the platform to host a FB live. SibsNY is a network dedicated to connecting the brothers and sisters of people with developmental disabilities to share information, resources, and support. The private FB group has 238 members and an email list serve of about 100 people.

The
how to

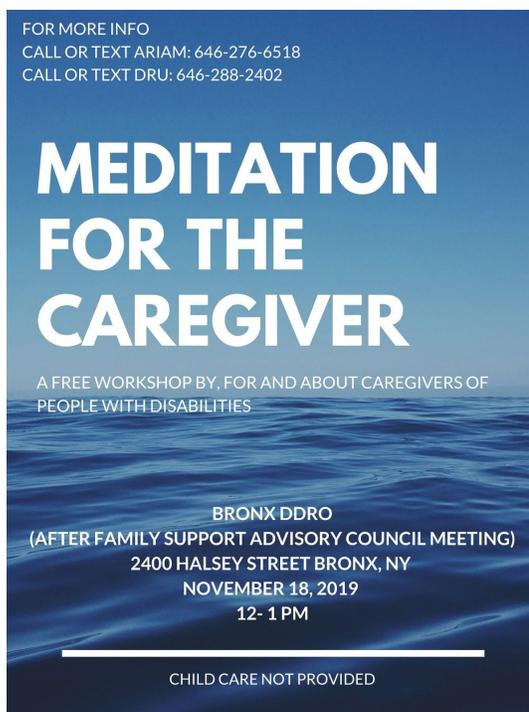
conversation got off to a rough start. I was challenged by my lack of knowledge of share everyone’s screens during the call. Facebook gave me error messages and eventually, after 30 minutes of talking

through the challenge with the siblings, one of them was able to share her screen. The other two joined through comments. The [video](#) ran for 40 minutes.

Link to the ethical guidelines you developed for your community in the law and ethics class.

- I created this 6-page report as part of my Community Guidelines assignment in our Legal Ethics class during the Spring semester outlining, at the time, how I had intended to protect myself from various legal issues including defamation, copyright infringement, plagiarism, and fabrication, working with confidential sources, etc. while working with the community.

Link to the interactive product or service that informed your community. Include a brief summary of your product/service and any relevant information about your approach.



Meditation for the Caregiver is the only free stress management class in the Bronx that benefits caregivers of people with autism and other developmental disabilities. In October, Dru had introduced me to her friend at an event in the Bronx. Her friend, Tina Veale, is the chair of the Bronx Advisory Support Council which is an advisory board of parent caregivers and self-advocates who meet once a month to discuss information about services, changes in the care system for people in the disability population and to pass general information. The council meets every month. We stayed at the event and passed around flyers. Dru and I reconnected on the phone shortly after the event to talk about whether it was a good idea for me to visit

Tina's group. I said I'd love to meet her and other caregivers from the council at an upcoming meeting, where I could also pitch our workshop. Tina had known a little about the workshop but hadn't shared that information with the caregivers until I showed up on October 18. The caregivers seemed interested and suggested that we host our workshop on a weekday (late morning, early afternoon) around the same time of their meeting. A woman with long red hair said we could have our workshop after their next community meeting which took place on November 18. In a week, I had a flyer and a web page set up and emailed it to Tina to send to the rest of the council. We showed up prepared and had our workshop on the 18th of the following month.

- Karla Arroyo is my mentee from the Class of 2020 Social Journalism program who showed up to support and help me [document](#) the event.

Link to at least one of the major assignments in the startup sprint course. Please annotate the link with a brief summary of what you did.

- I began to develop a bot with input from families in the form of paper surveys in October 2019. The bot still lives on the internet but I stalled the idea of releasing it to caregivers because of time constraints. I would like to revisit the bot in the future. Here's the crux of that [project](#).
- This [Medium post](#) summarizes what I learned during a ten-week Startup Sprint course. Realizing the power of empowering people who care for others to care for themselves through mindfulness and meditation has been the greatest discovery of my final semester in the Social Journalism program at The Newmark's J-School at CUNY.

Crowdsourcing Project

https://docs.google.com/forms/d/e/1FAIpQLSdoY2y_wwmZGnM9mX36BnnLAnT_x6rPsZByeSBIJTCHxWGlsA/viewform