

DISRUPTING UNJUST DISABILITY DENIALS: AN INTERVIEW WITH MIKA AOYAMA OF THE DISABILITY ADVOCACY PROJECT

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This is the second in a series of interviews with legal practitioners who are pursuing social change through their work. This conversation is between Mika Aoyama¹, a Senior Paralegal Case Handler in the Disability Advocacy Project² at the New York Legal Assistance Group³ (NYLAG) in Manhattan, and Roxane Picard, an intern at NYLAG.

ROXANE: What does the Disability Advocacy Project (DAP) do, and what is your role within it?

MIKA: The DAP focuses on disability denials. Our clients are people who have applied for either Social Security Disability (SSD) or Supplemental Security Income (SSI) and have been told by the Social Security Administration (Social Security) that they're not eligible because they are allegedly able to work. We help clients fight "overpayments"—

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1. Mika is a Senior Paralegal in the Disability Advocacy Project (DAP) at the New York Legal Assistance Group (NYLAG). She advises and represents low-income individuals with disabilities in appeals, terminations, and overpayments before the Social Security Administration. Mika has practiced in the DAP unit for two-and-a-half years. Prior to joining NYLAG, Mika worked as an AmeriCorps member at FECS Health and Human Services, where she coordinated a program providing interview attire to public assistance recipients. She has also worked in the Public Service Office of Brooklyn Law School and volunteered at the International Rescue Committee's refugee resettlement office in Oakland, California. Mika earned her Bachelor's degree at the University of California, Berkeley.

2. DAP works to ensure that eligible disabled individuals receive benefits under the Social Security Disability Insurance Program (SSD) and the Supplemental Security Income Program (SSI). Staff members provide free legal advice and representation when SSD or SSI benefits are wrongfully denied or terminated. DAP was founded in the spring of 2008. See <http://nylag.org/units/public-benefits/projects/disability-advocacy>.

3. Founded in 1990, NYLAG provides high quality, free civil legal services to low-income New Yorkers who cannot afford attorneys. Services include direct representation, case consultation, advocacy, community education, training, financial counseling, and impact litigation. NYLAG is unique for its ability to serve not only the abject poor, but also individuals and families who earn slightly above the government-designated poverty threshold, since it neither applies for, nor receives, federal funding. See <http://nylag.org>.

when Social Security claims they have paid somebody too much money and are now owed. We also help clients with suspensions and terminations of benefits, either due to financial issues or because Social Security claims someone's medical condition has improved to the point where they can go back to work. Day-to-day, this means that we conduct intakes with clients, request medical records, follow up on those requests, review medical records, write briefs, go to hearings, and do advocacy work in-person and on the phone with local Social Security offices.

ROXANE: Can you briefly summarize the difference between Supplemental Security Income (SSI) and Social Security Disability Insurance (SSD)?

MIKA: SSI is generally for people who have no work history, have a very short work history, or have worked for quite a while but haven't had very high earnings. SSD is for people who have been working for a substantial period of time and have been paying into the Social Security system. SSD requires that an individual have a certain number of "credits" (based on their age) in order to be "insured." Credits are earned by paying Social Security taxes, and you must be "insured" at the time you become disabled in order to qualify for the benefit.

ROXANE: How many cases do you typically handle at once?

MIKA: Usually I handle between sixty and eighty cases, and they're all at different levels of activeness. I have some cases where it's just a matter of waiting for the hearing to be scheduled, and other cases that I work on more actively—for example, I obtain medical records and write briefs.

ROXANE: What is the difference, if any, between what a paralegal in your unit does and what an attorney does?

MIKA: Because this is administrative law, I am generally able to do the same work as the attorneys, such as providing representation at a hearing. One difference is that I cannot be the representative who files legal papers in a federal case—for those cases, I can help prepare the filings but cannot file. Other than that, the day-to-day work is the same for attorneys and paralegals.

ROXANE: How is your DAP unit unique, if at all, amongst other organizations that do similar work in the city?

MIKA: Some DAP units within other organizations focus on specific boroughs, whereas we take cases from all five boroughs. We also tend to offer more assistance with overpayments than some other organizations. But, that's basically the only difference. All DAP units are funded by New

York state, so we're serving a lot of the same client population and doing the same work.

ROXANE: What incentive does New York state have to fund these DAP units?

MIKA: Individuals who apply for SSI frequently wait up to two years for a hearing, and during that time they're receiving public assistance, which comes from the state. Generally, there's an understanding where the applicant agrees that if they win their SSI case, a portion of their retroactive benefits will go back to the state because they wouldn't have been on public assistance had they been on SSI. This gets them off state benefits and on federal benefits.

ROXANE: How did you get to this point in your career?

MIKA: When I was in college, I started volunteering at a local refugee settlement office in Oakland. Most of what I did was helping refugees who had just come into the country apply for refugee cash assistance, which you receive in California, as well as for food stamps, medical coverage, and Social Security numbers. That was the first exposure I had to what it really looks like to navigate those systems. I'd see local area residents who had been waiting there all day and were being told, "There's nothing we can do to help you." That was an eye-opening experience for me.

I then moved to New York and worked at Brooklyn Law School in their public service office, so I became really familiar with the landscape of legal services organizations in the city. After doing that for a year, I decided I wanted to do direct services work. I did an AmeriCorps term at Federation Employment & Guidance Service (a nonprofit health and human services organization) and again was exposed to a lot of the challenges that are inherent in being a public assistance recipient.

When I finished my term there, I was able to start working at NYLAG a few months later. I like the work I do at NYLAG because there's a very tangible impact that you can have, assuming that you're successful. It's a system that frequently doesn't make any sense and it can be very difficult to find somebody who's willing to walk you through it.

ROXANE: Is it a difficult system because it's a federal program, so everything is very bureaucratic?

MIKA: Yes. There are also many rules and regulations that haven't changed in such a long period of time. For example, the entire decision that you're making when you're deciding whether or not someone is disabled for SSI or SSD is: can they work? For most people, that means figuring out whether there's any job in the national economy that they're able to do. Are

they capable of doing a job they've done in the last fifteen years, or is there another job they could do? What Social Security uses to decide that is, in part, the *Dictionary of Occupational Titles*, which has not been updated since 1991. So frequently, a big part of the decision in a hearing is "Can this person do any of the jobs in this big book of jobs that are from 1991?" Most people have never heard of those jobs.

I once had a client whose initial application was denied. One of the jobs that they listed in the decision—that the government argued our client could have done—was a dental floss packer. I have certainly never seen a job listing for a dental floss packer. I had a vocational expert talk in a hearing once about being a hand-bander—the person who puts a paper ring around plastic utensils which are rolled up in a napkin. Being a hand-bander is considered a valid position that the government can use in part to deny somebody's case. The Administrative Law Judges (ALJ) can make their denial of benefits based on the fact that somebody could have been a hand-bander. When they deny a case in that manner, the ALJ usually provides three jobs that they allege the person is capable of doing.

ROXANE: What are common misconceptions that people have about Social Security, disability, or welfare in America?

MIKA: I think a lot of people feel like public assistance recipients are lazy, and that these benefits are easy to get and keep receiving. There's also the misconception that there are so many people on these benefits who shouldn't be on them—people who don't seem "disabled." But, every day we interact with people who are not on SSI or SSD and should be. I think it's a tragedy. So many of our clients have to wait for such a long time to see a judge and it's possible that they won't win even at that point. In the event that they decide to appeal the judge's decision, they're looking at waiting another two years. During that time, people get evicted from their apartments. A huge number of our clients are dealing with serious mental health issues, which only deteriorate when they're going through the uncertainty of this entire process. It's not easy to get these benefits; it's an extremely hard process.

ROXANE: What's wrong with the system such that individuals who clearly meet Social Security rules for disability are denied and then have to wait another two years to get a hearing?

MIKA: Social Security contracts out to the states for disability determinations on applications. The Office of Temporary and Disability Assistance (OTDA) makes the disability determinations and they request records from the places where the client tells Social Security they've been

for medical treatment. That can be difficult because some of our clients have a very hard time keeping track of their doctors. When I'm looking at a client's records, I might note that a doctor referred the patient to another doctor elsewhere. I will then call my client and ask about that other doctor whom they haven't told me about yet. That type of thing doesn't really happen without representation. It's very easy for a client to just forget that they got treatment somewhere. Also, at times it's difficult even for us to obtain medical records, and the follow-up at the state level before these disability decisions are made is limited. OTDA will also send applicants for exams by consulting doctors. Evidence and opinions from treating providers are supposed to be weighed more heavily than the opinions provided by these consultative examiners, but in practice it does not always work out that way.

ROXANE: How often do you have to follow up once you request records?

MIKA: It's not unusual to fax a request four to five times. I recently had an office that I called over twenty times before I got any records. A lot of the big hospitals will get our requests, but they're very backlogged, so you'll have to wait a couple of months before you actually get the records.

ROXANE: Beyond the long waiting times, what other types of hurdles do these SSD/SSI applicants or recipients face?

MIKA: SSI is a program that's partly based on financial eligibility, so in addition to needing to be found disabled by the Social Security Administration, you also have to be financially eligible. For an individual, that means you need to have less than \$2000 in countable resources (cash, money in the bank, etc.). It also means that you can't receive much financial assistance from friends or family members, because that will either reduce or completely eliminate the amount of the benefit. There are a lot of technicalities for people to keep up with. Sometimes, there will be some kind of eligibility issue, such as a property overseas or cash surrender value on a life insurance policy,⁴ that a client doesn't know is a problem until it's too late. That can lead to really big overpayments, where Social Security states that they have paid an SSI recipient more than they should have received, and that recipient now owes those excess payments to Social Security. It's not uncommon for SSI overpayments to be several thousand

⁴ The sum of money an insurance company pays to the policyholder in the event her policy is voluntarily terminated before its maturity or upon her passing.

dollars, and sometimes it can be tens of thousands if it has taken a long time for Social Security to catch the issue.

It can also be very difficult to communicate with the Social Security Administration even if you're trying to do your best to report changes to your income and resources. It is not unusual to have to submit documents multiple times. A lot of our clients are not aware that just because you brought it into Social Security, that doesn't mean it was entered into the system. Just because you faxed or mailed it, that doesn't mean they got it. Often it's necessary to go in person, which can be taxing for our clients with serious physical or mental health issues. You're asking them to wait an entire day in a Social Security office, where sometimes there aren't enough chairs for people. It can be very difficult to advocate for yourself in a situation like that.

ROXANE: What is the maximum amount a person on SSI can receive?

MIKA: The maximum federal SSI benefit is \$733 a month. That is supplemented in most cases by either \$23 or \$87 from New York state, depending on the individual's living arrangement. So the most that someone on only SSI can get is \$820 a month. With that, they're expected to find a place to live, pay for any food that's not covered by the food stamps they would (hopefully) get, and pay for their phone bill, clothes, and transportation.

Also, the amount in benefits does not take into consideration the cost of living based on location. An individual who's paying for rent, utilities, and food in Kansas, and an individual who's doing those same things in New York City, will receive the exact same amount of money with no consideration for the huge discrepancy in the cost of living between those two places.

ROXANE: How do you deal with the emotional toll of your work?

MIKA: I think self-care is really important. I don't think I'm very good at that! But I think it's important and I hear it's good for you. Today's been difficult because I found out that I have a hearing scheduled in five days that I just decided to take on. But I also won two cases today, which helps. You try to balance things. If I have to give someone bad news, it's also nice if I can give someone good news.

You also have to learn not to take it personally. Sometimes I've done absolutely everything that I can do, and I still lose. It is really frustrating to feel like there are a lot of people who slip through the cracks—a case can be almost impossible to win in practice, even if the regulations do not necessarily preclude it.

ROXANE: Do you ever encounter bias or discrimination in your work?

MIKA: Sometimes the whole system feels biased. What makes the system so hard to navigate for our clients is exactly why they're interacting with the system. You're interacting with the Social Security system because you have to in order to obtain or maintain your benefits, and that is so difficult for you because of your physical or mental health condition, which is the reason you're receiving or applying for these benefits.

I've seen clients be treated poorly by local office employees. When I was at a local office last week, I had a 9:30 a.m. appointment; I was seen at 2:30 p.m. We left at 5:00 p.m. There were people who were told that day that they couldn't be helped. There were people who had early appointments and left because they couldn't handle sitting there anymore. Their benefits might get turned off or be reduced. People are not always advised about their appeal rights. It's horrifying to think of the number of cases that we see, versus the number of people out there who believe what they were told about how there was nothing that could be done. Their benefits have stopped or they've been told they owe Social Security money, but that may be totally wrong.

ROXANE: What would you say has been your greatest victory as a practitioner?

MIKA: Recently, I had a client who was a child on benefits because he has Down Syndrome. His mother was receiving his payments on his behalf. Social Security used her 11-year-old daughter as an interpreter during a local office appointment. The mother was a Spanish speaker; it is not that hard to find a Spanish interpreter. There was a series of misunderstandings, which eventually led to Social Security believing that the family had excess resources based on the father's assets. However, the father's resources are only supposed to be counted against the family if he resides in the house, which he didn't. Social Security came to believe that he lived with the family through this series of miscommunications.

As a result, they turned off the son's benefits and charged the mother with an overpayment. The mother tried to talk to the local office about this issue many times. At one point, she was told that she should leave it alone because it was a Pandora's box—that she wasn't eligible anymore, and that was the end of the story. She came to us and we filed an appeal, which was late. I argued it was late because she had never been appropriately advised of her rights to appeal, which she should have been advised of since she had been to the office several times to express her disagreement with the decision. Quite a bit of advocacy and a couple of appointments later, the

overpayment was removed, they got their benefits turned back on, and retroactive benefits were paid back for the last few months they hadn't been paid.

ROXANE: Have you considered switching to another practice area?

MIKA: I'm pretty happy where I am. What I find interesting about this job is that even though my practice is generally restricted to Social Security, most of the time that is not my clients' only legal issue. I get to learn a bit about food stamps, public assistance, and housing. Even strictly within the Social Security world, there are always new things coming up: new issues a client has, new medical conditions I haven't encountered before, new judges, and all kinds of new issues. You could do this forever and still have new things to learn, even though it's a system that hasn't changed much in decades.

ROXANE: Is there anything you think is important to mention that I haven't asked about?

MIKA: Early deposits. Part of SSI eligibility is making sure that you qualify based on your resources, which they count as of the 1st of the month. Social Security is able to verify with the banks what your balance is in your bank account on the 1st of the month. Generally speaking, SSI is also deposited on the 1st of the month. There are also, however, several months during each year when maybe the 1st is a Sunday or a holiday and the SSI payment comes in early. It's scheduled by Social Security to be deposited into your bank account early, on the 29th or 30th of the previous month. That amount that they put into your account is not supposed to be counted as part of your resources on the 1st, but sometimes it is anyway. I find this issue particularly frustrating, because it's Social Security's own money—they put it there!

I personally have never seen a case where Social Security has already accounted for that early deposit. They don't check. The conversation you always hear with SSI is that there are people who are defrauding the system, but there are also all of these people who are repaying Social Security for money that they don't owe.