A Mutant from Planet Cripton

AN ORIGIN
The Nerds of Color blog (April 3, 2014)

In 1974, a baby arrived in the suburbs of Indianapolis, Indiana, from the planet Cripton. She looked like the offspring of two Chinese immigrants, Ma and Pa Wong, but something was different.

Earth’s gravitational force made it difficult for this baby to raise her head. She couldn’t crawl and went straight from sitting to walking. Perplexed, Ma and Pa Wong took their baby to the doctor and found out: she is a mutant from Cripton!

This is her origin story.

This baby alien learned the ways of the Normal quickly; by watching Sesame Street and reading books, she immersed herself in the cultural mores around her. She communicated and moved in ways that wouldn’t scare the kids on the playground; she knew how to talk to adults when they routinely poked and prodded her. Eventually she grew up and realized that she was not alone, that there were other mutant Crips!

As she came into the age of ascension, Alice (her Earth name) embraced her identity and found power in the community of fellow Crips around her. Scrutinized and labeled deviant by the authorities, Alice and her Siblings of Cripton continue to fight for social justice and equality for mutants and nonmutants alike, even as they face discrimination and oppression for being the Other.
So that is my mash-up nerd biography. It’s true, I was born in 1974 to immigrants from Hong Kong, and I am a crip. It’s an understatement to say my love of all things science fiction and cartoons intensely informed my identity as a disabled Asian American woman.

I actually do have a mutated gene—I was “born different” from most babies with a type of muscular dystrophy. I grew up hearing terms such as weakness, congenital, defect, pathology, and abnormal associated with me. I didn’t realize the way it assaulted my personhood. Those words transformed into sources of power and resistance as I fell into my imagination through reading, writing, and watching a whole lot of television.

I stopped walking around the age of seven or eight. This separated me from most of my peers who took part in activities that I couldn’t keep up with. Television and the library became my sanctuaries. I distinctly remember being the first person up every Saturday morning because my favorite cartoon, Super Friends, was on at 7:00 a.m. I think it was my first time seeing an Asian character, Samurai, in a cartoon (and no, Hong Kong Phooey didn’t count), flying around with his cyclone torso. It was the first time I saw a superpower as a “special” ability. Super Friends was a unique minority that was valued yet not fully understood.

In elementary school I read Madeleine L’Engle’s A Wrinkle in Time, and it blew my mind. Many books later, I discovered Octavia E. Butler, and then my mind really became blown. In the trilogy Lilith’s Brood, the Oankali are incredibly perceptive and sensitive aliens. They do not understand humans’ fear of difference. To them, genetic variation is a positive, not a negative.

Like with Super Friends, I developed an affinity for ensembles such as Star Trek: The Next Generation, Star Trek: Deep Space Nine, and, of course, X-Men: The Animated Series. To have one of the most powerful mutants of them all, Charles Francis Xavier, be a man in a wheelchair absolutely delighted me when I started watching the show in 1992. It was like, “Fuck yeah, just try to talk down to me. I’ll implode your mutant-hating heart.” Actually, that’s more like Magneto’s attitude. Professor X keeps things calm and cool. He commands respect, and his competence is never questioned.

Themes and characters in the X-Men universe resonate with so many communities: LGBTQ+, immigrants, and people with disabilities. The story lines ask a lot of complex questions about assimilation, identity, morality, militarism, and diversity.

There’s something incredibly affirming about seeing yourself reflected in popular culture. In the science fiction, fantasy, and comic book worlds, we may identify with characters like us, characters unlike us, or characters we want to become. Professor X is someone I identify with and aspire to be (although my temperament is a bit more like Magneto’s).

Nerd culture—in books, movies, and television—filled...
me up and transformed the way I viewed my disability since my nascent origins. Who are nerds if not those left out, ridiculed, neglected, and undervalued by dominant society? Who are nerds if not those who embrace difference, seek community, and support the powerless?

Lessons from a Chinese School Dropout

When I was growing up in Indianapolis, Sunday nights were filled with last-minute attempts to finish homework and thoughts of dread about going to school the next day (Garfield was right about hating Mondays and loving lasagna). Sunday was the day for another activity that I was not good at: Chinese school, which took place in the afternoon after Sunday school and lunch. The church was the center of my Chinese American universe, where I learned about community, identity, and culture.

My sisters, Emily and Grace, and I grew up with a small gaggle of second-generation Chinese Americans close in age: Amy, Wayne, Ellen, Simon, Sang, Ming, Mark, Jeff, Jemie, Iris, and a few others. Summers were marked with the moms gathering together for 婦女会 fú nǚ huì, a women’s group that met for Bible study and social hangouts, where they would learn to make things together such as Auntie Anita’s (Ellen and Simon’s mom) 花卷 huā juǎn, magical steamed buns with green onions folded into delicate, petal-like layers of dough. The kids (except me) ran wild like feral hogs, and Auntie Jean (Jemie’s mom) gave us ice pops in long clear plastic packets that were basically tubes of frozen sweetened water in artificial rainbow colors. She would cut the top off the plastic tubes, and voilà! Oooh, they hit the spot. Garage sales, potlucks, birthday parties, home perms and haircuts (oh, the hu-
The Americans with Disabilities Act

An interview with Rochelle Kwan (July 26, 2020). This conversation has been condensed and edited for clarity.

ROCHELLE KWAN: One of the reasons I’m really excited to have this conversation with you is because this year is the thirtieth anniversary of the Americans with Disabilities Act, the A.D.A.

ALICE WONG: Yeah. And I love how you are younger than the A.D.A.

ROCHELLE: [laughs] I know!

ALICE: Oh, I love that because this is so funny. ‘Cause I think—I don’t know if we would call this an intergenerational conversation, but I guess it is, right? I think it is. So it’s really a delight to also talk to you about this. So, I was sixteen, a sophomore in high school, when the A.D.A. passed. And to be totally honest, I don’t really remember that much about it. I mean, I think at that time in my life, I was not really all that connected with any sort of consciousness about having a disabled identity other than my own kind of diagnosis. And I know that I was disabled, but I never said the word disabled, you know. And I think that was just the time I grew up in and you know...I struggled. I think I felt already, just being a teenager, no matter what decade you’re in—it’s a lot! I was uncomfortable in my own skin. I felt ashamed of myself. Like, I was embarrassed. I was like, just, you know, I really wish, as a wheelchair user, I would just melt in with the background, but I never could. I just really wanted to be invisible sometimes because I felt so hypervisible, you know.

I didn’t have any role models. I did not have any adult in my life that also had disabilities, that ever said, like, “Hey, I’ve been where you’ve been. It’s going to get better.” And I also wonder, if I had that, would I have accepted it? Because I was in such a place where I was just uncomfortable. I was, to be honest, embarrassed to be around other disabled kids; sometimes I didn’t wanna hang out with them because I so wanted to just be like everybody else.

ROCHELLE: Yeah. It sounds like you weren’t connected with not only the disability community, but you weren’t connected to the identity of being disabled. Before you came into that identity, did you think of it as just, like, This [is] something that I have to deal with on my own?

ALICE: Yeah, I think I definitely started after the A.D.A. was passed and just being a little bit older, as a teenager and reading and learning more. I just realized, Oh my gosh. There are things going on in this world that are beyond my little world. And I think one of the first things I read was in Time magazine, there was an article about accessible transportation. And it’s right around the time that the A.D.A. came out. And at the moment I read that, I was just so floored by the idea of an accessible bus. And this is like, you know, you gotta imagine this: back then, it was just really rare. And I thought, Wow, what would it be like to live in a community where I could leave my house and take a bus or a train all by myself? I mean, at that point in time, I lived in the suburbs. My parents drove me everywhere. I did not have a driver’s license and of course a van modification would be costly, so I didn’t go through the typical rites of passage that all my friends did. I just felt very stymied. And reading about other places like Berkeley, California, which, really, it was an epicenter for disability rights and just accessibility in terms of California as a state, that really also planted a seed that, hey, there are disabled people living right now in a world that’s much better and a world that’s much more accessible. And then one day, maybe I could have that, too. Back then, it was a dream.

You know, I actually wrote a letter to the editor, and it was published in Time magazine. And I think that really was, when I was still in high school—that might’ve been the start of being on that
journey of identifying and also being kind of engaged with the world. It was an awakening as I got older, graduated from high school, and definitely when I went to college and really learned a lot more about disability studies. And I kind of realized all this stuff that I did for myself isn’t gonna help other people and isn’t gonna make a difference. So it’s really about systemic change. And I think that was a real switch for me as I became a college student and then went to grad school. I realized I could find so much to get something better for myself, for my accommodations as a student, but until we actually change policies, the next year, another student’s gonna have to do it all over again. And that got me angry. I think that’s what really drove me to think, How can we do this? How can we make a difference? How can we work with others? Because it’s not just about what I care about. It’s not just about what I need, but what all kinds of people need.

ROCHELLE: And I guess when the A.D.A. started, did you imagine the A.D.A. as that alternative world, that better world for the disabled community?

ALICE: I think people have a lot of misconceptions about the A.D.A. I think there’s a lot of expectations, but it did not, let’s say, solve everything, you know. Things didn’t just magically become better overnight, especially in 1990, when it passed. I think it took a lot of years after it passed for all of us to see the changes, right? Like curb cuts, elevators, just some of the very basic things that we take for granted. All of the things have to still be fought for even today. But I will say that what the A.D.A. did was [give] us a law that we could call our own. It was the law that was for us, and it was the law that’s enshrined in our legal protections. There were other laws before that, but the A.D.A. really was the one we could use as a tool. And I think it’s a tool. It’s just the beginning of creating change. And the law can only really do so much. I think sometimes we put too much stock into laws, because it’s really about the spirit behind the law. What does it really mean when we say that you belong in the public like everybody else? And how do we get our culture to that place where everybody believes that? And I don’t think we’re—you know, it’s sad to say, but thirty years later, we’re not at that place yet. We’re nowhere close to it. Change does not happen easily, and there’s a lot of people who are afraid of change, especially those in power. And there’s a lot of people that know the value of inclusion, especially with disabled people who’ve had a history of being segregated and institutionalized.

ROCHELLE: That is one thing that I have been thinking about a lot recently, is this, as we’re in the middle of a pandemic and everybody is at home. Folks are tapping into these methods and organizing strategies that the disability community has been using forever, you know! And have built their communities from. And are people giving credit to the disability community?

ALICE: Yeah, real talk. I mean, it is ironic and a little bit bittersweet that there were conferences years ago that I couldn’t attend because I would need to participate via videoconference. But my goodness! Look how quickly so many conferences are now virtual.

ROCHELLE: Yeah.

ALICE: So many people, disabled people, would get turned down for jobs when they asked to work remotely. And now many people are working remotely. And I think that’s a very painful sticking point, because there’s still major disparities in terms of the employment rate. So, every law is imperfect, right? So one thing about the A.D.A. is that there’s really no way to enforce it. There’s no A.D.A. enforcement to check on businesses, right? So, basically, for a large part, when disabled people make accommodation or access requests, and if they’re thought of as reasonable requests, an employer still might treat it like a burden. And I think that still is a reason why so many people are afraid to even ask for them. I think that’s one of many reasons why so many people aren’t in the workforce. And there’s a lot of reasons why people don’t even disclose that they have a disability in the workplace. Because they don’t wanna be seen as different. And I don’t think anybody enjoys filing a complaint or lawsuit, but that’s one option.

[ROCHELLE chuckles]

ALICE: Most of the time it’s trying to rectify an unjust situation.

ROCHELLE: Mm-hmm.
ALICE: If there's any message I could share with people who are not disabled, it is the fact that access is so much more than just compliance with the A.D.A. Access is something that we all have capacity in some way or another, to give to one another. So whether it's... hey, you know, if I say, "Oh, hey, Rochelle, can we talk after tonight instead of tomorrow morning? I had a bad day, or I'm just tired," you could say, "Hey, yeah. No problem." That's a form of access, right?

ROCHELLE: Do you have any last words about the D.V.P. [Disability Visibility Project] as a celebration of the A.D.A. and also a push to continue to better the present and future?

ALICE: Yep. You know, I think as we think about thirty years with the A.D.A., there's a lot to be thankful for. And I'm really just looking forward to the future and thinking about and dreaming big about what's possible. There's so much work to be done. The struggle continues. There's so much to critique and to be mindful of. But there's also so much hope. And I think with younger people—it just makes me so happy to see kids who are growing up with a community [that's] ready and welcoming them. That, to me, is just magical, to be part of this older group who is welcoming the next generation and future generations. And I know, I just know, things are gonna get better. And things are better now than we had thirty years ago. The possibilities are endless.
One of Those Aha Moments

An interview with Eric Koenig, former director of the Office of Student Life at the University of California, San Francisco (U.C.S.F.), at StoryCorps San Francisco (October 25, 2014). This conversation has been condensed and edited for clarity.

In 1987, there were two students with disabilities at U.C.S.F. By 2013, there were more than one hundred fifty students with disabilities. As a new student to U.C.S.F. in the late 1990s, Eric was one of the first people from the school whom I met.

ALICE WONG: I was a prospective student thinking about going to U.C.S.F., and I distinctly recall being very apprehensive, especially being from the Midwest and contemplating a move and the idea of going to graduate school plus having a visible disability, worrying about housing—you know, just basic how-to-live questions.

And I made a cold call through the directory, found your name, and you called me back. And I remember it was like in the evening in Indiana, and you were just so open and willing to talk about, you know, the challenges and what U.C.S.F. could realistically offer me, and I think, to me, that was just a revelation, because it was such a generous and wonderful gesture to have this conversation, and it really gave me some sense that there was a possibility that I should pursue this. So that led to a trip out to U.C.S.F., where I met with
you, and I think we talked a lot about what if, what kind of plans would need to be made if I was accepted. We’re not assuming I was accepted, but if I was, what were the plans in place that we would have to make.

**ERIC KOENIG**: I remember we had a number of conversations, and I guess I had been waiting to meet you before you contacted me. And I didn’t know who would actually call, and you were the caller that I was expecting for a few years previous to your call. In some ways our timing was very good, because there were accessibility issues at the university, and you were asking about some very specific issues that needed to be resolved, housing in particular. And I think we both quickly understood one another [so] that there was a very collaborative style to begin with in our conversation, and as you articulated some of your concerns, I was able to articulate either how we could accommodate you or at least an attitude and a willingness to accommodate.

**ALICE**: Mm-hmm.

**ERIC**: And so I think, you know, our main issue was really about the lack of accessible housing; there really wasn’t any appropriate accessible housing.

**ALICE**: As I recall, it was right around that time the Aldea San Miguel student housing was still being built, and I think that would have been the accessible housing, but it was not available yet. So I think, you know, the main message that you communicated to me was that U.C.S.F. is somewhat small and unique and the sense that, you know, we can definitely try to figure things out together.

**ERIC**: Right.

**ALICE**: And I feel like U.C.S.F., at that time when I applied, was at a really interesting moment when I was able to get customized, individualized assistance, and that’s really unique. Once I was accepted, many processes were put into motion. You connected me with the director of housing, and they did some renovations to faculty housing on Fifth Avenue, which is only a block away from the main campus. Within several months, I believe, the Housing Department was able to retrofit a bathroom, and that apartment was already on a garage ground floor. But it was really getting an accessible bathroom—that was a major thing to do, because that takes a long time to fund and plan any sort of change or renovation, and the fact that U.C.S.F. was committed to having this done before I arrived really meant a lot to me as a student because, you know, I already felt so [laughs], you know, really, like, singular in a lot of ways.

I am certainly not the first student with a physical disability at U.C.S.F., but I feel like [one of the few]. There have been others, right, to your knowledge?

**ERIC**: Yeah. The campus was an interesting mix of being kind of behind the curve in terms of being accessible, but also, we did really well in responding when students were coming with whatever needs that they may have that we were not equipped to deal with. And so I think what I was trying to communicate to you in our phone calls was, if you’re willing to be a pioneer and be the first one and understand that change will need to occur, I believed that the change would occur. And so we weren’t inaccessible, or we weren’t properly accessible [laughs], I should say, but by being present and by being willing to accept some temporary accommodations that you and your family were very gracious about, you understood that by coming
to campus, the campus would then make the changes that were you
know, appropriate and accessible.

I just wanna comment on your ability to connect with people and
to educate and advocate and to assess an institutional environment.
Your instincts around how to prompt change are just superb. And
you’re also extremely adaptive [at] figuring out, you know, who the
allies are and how to connect with steering committees, advisory
groups, and so those are really important attributes. It’s not always
easy for people with disabilities who are in environments [that are]
not as accommodating as they would like [them] to be. It really
represented a really positive model of change: how to connect
with the members of the community and to help them understand
some of the challenges and really effect change that improves the
environment for everyone, not just people with disabilities.

ALICE: Well, I really do feel like we were equal partners in this. And
that’s what most people wouldn’t imagine between a student and
an administrator; you know, having this kind of power dynamic but
I really feel like we both worked so well together at these broader
aims. And there was this opening, but I think part of it, too, is the
institutional culture at U.C.S.F. When I arrived in ’97, there were still
a lot of issues and, you know, that was all laid out clearly for me, and
I accepted it, and I thought, I think I can work with these people on
campus to make it a better place.

ERIC: The style and attitude with which I used to approach my job, or
at least my area of services for students with disabilities, was really
that the students were the experts, and I needed to know from each
student what their needs were, especially in cases when, you know,
we hadn’t served a student with a particular disability or requiring a
certain kind of accommodation or facing a certain set of challenges.
I was always interested in knowing what worked for the student
before. I got a lot of guidance from students, and I got a lot from you.

It was fun to see how the A.D.A. started to change things. There
was a large committee [of] all the different stakeholders that were
affected by changes in accessibility requirements: parking and
transportation and facilities design, the architects and designers
and so forth on the campus. And so there was a large group that
was formed and certain changes were prioritized right away. [But] beause of budget, not everything was done, and you know, later on
when you arrived, you pointed out the elevator buttons were vertical,
and some people who use chairs couldn’t reach the higher buttons to
get to the higher floors.

ALICE: ‘Cause there’s, like, so many floors and there’s, like, several rows
of vertical buttons. There’s absolutely no way to [reach them all from
a sitting position.] And I remember we met with one of the people
in facilities management or an architect, and I proposed adding an
additional panel, a horizontal panel, and he’s like, “Oh, we can do
that!” And now there are horizontal panels on these elevators that
are used by visitors, patients, staff, students, and whenever I see it,
it makes me smile, because I know that it started with my individual
need, but these simple accommodations really make a difference in
everybody’s lives.

ERIC: It’s the universal design.

ALICE: And I notice in elevators able-bodied people who—let’s say that
the elevator is full—they’ll use the side buttons because they are by
the side of the elevator door. They can’t get to the front where all the
buttons are, so I see how everybody is using them and that makes
me so happy.

ERIC: The elevator-button story is, I think, one of the greatest ones
that we worked on [while] on campus, and I, too, whenever I walk

Horizontal and vertical elevator buttons inside an elevator at the U.C.S.F. Ambulatory Care Center, 490 Parnassus Avenue, San Francisco.
in an elevator on that campus, I actually think of you. [It] is a really beautiful story about how change occurs, because what happened was, if I'm recalling this correctly, the Muni stop [at Arguello Boulevard and Irving Street] was made accessible, which gave you much better options for traveling independently on public transportation. The bad news was the stop was near an elevator in the dark corner of a basement of a building. [And] one evening at ten thirty or even at night, you were waiting [by yourself because you couldn't reach the buttons inside] the elevator. And that's a safety problem, and I immediately thought, okay, one, this change should occur. But two, you know, a member of our campus community or a patient or visitor could be compromised in a position, you know, of safety. And so we used that and got together with key people. And I think we actually went to an elevator . . .

ALICE: I think I had [to demonstrate it,] and I think having a real person who uses it really sealed the deal for these engineers. And they were like, "Oh, yeah, we can do that." They saw and they got it.

ERIC: Right. It was one of those aha moments where people who are in design positions and maintenance positions never—it never occurred to them.

I really love this story, because the campus has a lot of elevators, and at first, the folks we were dealing with, you know, looked at it and the wheels were turning, going, "Yeah, we should do something," and then the dollar signs were starting to turn over. And so the approach that we took was, well, what are your paths of travel?

They were managing the budget issues [and] wanted you to be accommodated, but they then made a commitment, and every time an elevator was gonna be renovated a horizontal pattern would be included. I thought it was just a beautiful example of an institutional change, recognizing that a member of the campus community could not freely and independently move around the campus, so they let you provide a list and say, "Here's where I go."

ALICE: Yeah.

ERIC: And they did it. Ultimately, they didn't even wait to renovate the elevators. They just started putting them everywhere. Again, you were in a position to point out a need and did so in a very gracious, certainly assertive [manner], and you engaged the right people.

ALICE: And this is where [this] partnership works, where you connect with your [colleagues], and you were with me in these conversations and meetings and that added a lot of weight. It wasn't just this student coming to see this engineer or architect. It's this idea that offices that serve students with disabilities really should be the advocates and allies of the student.
Why Disabled People Drop Out

A TWITTER THREAD

Alice Wong 王美華 @SFdirewolf · Apr 24, 2019
Really appreciating everyone’s powerful stories with the #WhyDisabledPeopleDropout tag.

Here’s my not-so-brief story.

I loved sociology ever since high school and knew the humanities & social sciences was my jam. [thread]

Alice Wong 王美華 @SFdirewolf · Apr 24, 2019
Replying to @SFdirewolf
I experienced a major healthcare crisis in my first year of college that forced me to take time off. When I was ready to return, there were cuts to Medicaid in my state that decreased my hours of home health aides.

Alice Wong 王美華 @SFdirewolf · Apr 24, 2019
Paying college tuition on top of attendant care was exorbitant and unrealistic. I decided to stay home & commute to my local university. I would then plot and plan my way out of Indiana. While it was rough, I found some great friends & teachers during my undergrad years.

Alice Wong 王美華 @SFdirewolf · Apr 24, 2019
I wanted to be like my professors: writing, researching, teaching. Creating knowledge. Disabled scholars like Irving K Zola & Barbara Waxman Fiduccia were the few out there who gave me hope. The same for the historian Paul Longmore.

Alice Wong 王美華 @SFdirewolf · Apr 24, 2019
I was strategic in applying for PhD programs in California and was thrilled to be accepted in a medical sociology program where I wanted to focus on the sociology of disability & qualitative research

Alice Wong 王美華 @SFdirewolf · Apr 24, 2019
Hoooh whee, I felt like such a suburban bumpkin when I arrived. There were about 7 in my cohort and everyone was so sophisticated & smart, some with already established careers & multiple degrees.

Alice Wong 王美華 @SFdirewolf · Apr 24, 2019
I was one of the few physically disabled grad students at this health sciences campus and was a guinea pig of sorts on accessibility & other services for students w/ disabilities (late 1990s)

Alice Wong 王美華 @SFdirewolf · Apr 24, 2019
2 things immediately became clear in my first few years of grad school: I struggled academically and felt completely out of depth. I also hit a wall of sorts, I didn’t realize how hard I’ve been pushing my body/mind ever since junior high. I was spent and could not keep up.

Alice Wong 王美華 @SFdirewolf · Apr 24, 2019
I ended up taking incompletes and kept renewing them. It was awful because I felt guilty and the longer it took the more stuck I felt. It got to the point where my advisor met with me and gave me an ultimatum to finish my coursework and complete my qualifying exams

Alice Wong 王美華 @SFdirewolf · Apr 24, 2019
And dear reader, I stuck to the agreed upon schedule and finished the work. The question was whether to advance and start the dissertation phase. It seemed impossible to complete a PhD based on me barely getting by the first 2 years. I felt like a failure.
My Day as a Robot

Resistance to assistive technology is futile. As a sci-fi nerd, I have to make a Star Trek reference whenever I talk about technology and disabled people. The disability community is living in the darkest timeline right now—at least, that’s what it feels like under the Trump administration in the United States; yet at the same time we are living in an age of the internet, social media, and technology, which have revolutionized the way we connect, communicate, and participate in social life.

While activists continue to fight for disability rights and against attacks on the safety net and multiple marginalized communities, it’s important to take time and reflect on the amazing, fun things that happen to all of us. This is one of my stories.

In 2015, I was invited to the White House for a celebration of the twenty-fifth anniversary of the Americans with Disabilities Act. At the time, I served as a member of the National Council on Disability and had launched the Disability Visibility Project the year before. I don’t travel anymore by plane for a number of reasons and did not plan to attend. This is a fact of life, and it took some time for me to adjust and reconcile. It’s a major bummer to miss meetings, opportunities, and social events because of my disability (and larger systemic factors), but I’ve reached a place where I try to focus on ways I can participate remotely or behind the scenes. FOMO