



## **NCAPPS Webinar Transcript: “Person-Centered Supports in Popular Culture”**

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### **SPEAKERS**

Andy Arias, Kathy Flaherty, Finn Gardiner, Mary Radnofsky,

Bevin Croft, Alixe Bonardi, Miso Kwak

### **Alixé Bonardi**

Greetings everyone, my name is Alixe Bonardi. I am one of the co-directors of the National Center on Advancing Person-Centered practices and systems, we're delighted that everyone is joining us here. And we apologize, we apologize for a little bit of a slow start today as we had a couple technical glitches as people are joining this webinar, I would like to express my greetings to you, and also to provide a description of myself, I am a white, middle aged woman with shoulder length, brown hair. I'm wearing glasses, a white and green shirt, and I have a bookshelf in my background, and a plant. So next slide please Connor. So welcome. I'm joined here by our co-director Bevin Croft, who will be facilitating a portion of the question and answers at that later in the day and also by two important team members, Connor Bailey and Miso Kwok, who were also really essential to the work we're doing today. Thank you. And thank you all for joining us to learn about person centered supports in popular culture. This webinar series is sponsored by the National Center for Advancing Person-Centered Practices and Systems, which is funded by the Administration for Community Living and Centers for Medicare and Medicaid Services. All NCAPPS webinars are free and open to the public, and we are delighted to see as many people joining, and beginning to drop in a chat to each other in in the chat. Keep it going, guys. Okay so next slide please. As a reminder, The goal of this center, NCAPPS, is to promote systems change that makes person centered principles, not just an aspiration, but a reality in the lives of people across the lifespan. And



we accomplish this through a variety of means, including these community, these discussions with, with a broad range of people from our communities, to think about how to integrate person centered principles and to learn from as many places as we can, including popular culture. Next slide please. A few webinar logistics to run through. This is a webinar format so participants will be muted during the webinar, you can use the chat feature in zoom and I see people have certainly started doing that to both communicate with each other to say hello and to post questions towards the end of the webinar. Our speakers will have an opportunity to respond to your questions as you're dropping them in so please don't hesitate to, to add in questions or comments, excuse me, throughout this this discussion today. This webinar will be live captioned, in English and Spanish. To access the Spanish captions, please use the link which is shown on the screen and we will be dropping that link into chat as well it's right there in chat. It is also available, available. There will also be live captions in English that you can access directly in zoom this live webinar does include polls and evaluation questions, so please be prepared to interact during polling times. Next slide please. After the webinar you certainly can send follow up questions and feedback about the webinar or other questions you have to our web address our email address "ncapps@hsri.org". Please note this email address, isn't monitored during the webinar, and this recorded webinar along with with supporting materials will be available on the our end caps website at [ncapps.acl.gov](http://ncapps.acl.gov). Next slide please. And this is one of the polling times -- to begin this webinar, we would love to know who is joining us here for this discussion. And there should be a poll that is popping up on on your screens, asking how you self-identify. There are eight selections that you could choose from. And, and we ask you to enter all that apply. I see answers pouring in in chat and I think people should be able to, to see as people are resulting we'll give it another 10 seconds or so, as people are entering their responses. Wonderful. And here we have an here we have, who is joining us today. We have folks have the majority of people it's kind of a split between people identifying as social workers, counselors or care managers and working for service provider organizations, researchers a few, we have 5% people, like identify was a person with a disability, and additional 15% family members or friends and self-advocates at 15% are joining us, and also 5%



also identify as as peer specialists or peer mentors, terrific and we are glad to have all of you here. Thank you so, so with that I would like to go to the next slide, and I would like to turn it over to my colleague Miso Kwok, who will be taking us through the next part of this discussion, beginning with an introduction to today's speakers.

### **Miso Kwak**

Hi everyone, this is Miso speaking, Alex thank you for the introduction and walking us through the logistics and access things -- just for housekeeping purposes I'm aware that the Spanish link on the chat may not be working, and Connor just a side note, if you check the email, you will see the correct link that should be working, I believe. So if you're trying to access the Spanish. Spanish captioning. Thank you for your understanding and patience. Okay, so just to briefly describe myself. I'm an asian woman in my 20s I'm wearing. Most notably, it's something that I want to bring people's attention to is that I'm wearing a white-cane earring. And for this purpose of today's conversation, I want to share with everyone that I identify as a disabled person, and specifically a blind person. So thanks so much for joining us today. I'll start with the speakers that we have today. So first, we have Andy Arias. Andy is an actor, producer, and advocate. He has produced many films, including The Unicorn Closet, and Extra- Special. He is currently producing the documentary. Danny's Twins, and in his work he strives to create true portrayals of people with intersecting marginalized identities. Andy he also works as an adjunct faculty at Georgetown University where he highlights the crucial role of media and its ability to influence and shift perceptions, and then we are joined by Kathy Flaherty. She is the executive director of Connecticut Legal Rights Project. It is an agency that provides legal services to low income people with mental health conditions on matters related to their treatment, recovery, and civil rights. Kathy combines her personal experience as a psychiatric and long-COVID survivor, and her legal background, to speak to issues affecting people with disabilities. Kathy lives with her family and rescue cat Stella, and you can find her on Twitter and she has written in various topics. Next, we have Finn Gardiner who is a disability-rights advocate with interest in educational equity, intersectional justice, comparative to policy and



inclusive technology. Finn holds a Master's of Public Policy degree from the Heller School for Social Policy at Brandeis University, and Finn is currently working at the current as a communication specialist at the Lurie Institute for Disability Policy at Brandeis University. Last but not least, we have Mary, Radnofsky, who is a former ghost-writer and College Professor of Education and human development, French, astronomy, and qualitative research. She founded and ran the Socrates Institute, a nonprofit educational organization for over 20 years. Dr Radnofsky, who has had vacuolar angiopathy for over 15 years, is the first person with dementia to speak at the United Nations regarding the conventions on rights of persons with disabilities. She has a travelled globally with her medical alert dog Benji, and she discusses various topics and speaks for people with dementia. So, we have a such an exciting panel to talk to you all about how disability support and system are portrayed in our popular culture. So we'll get started with Kathy. Kathy, the floor is yours.

### **Kathy Flaherty**

Thank you so much Miso. Again, my name is Kathy Flaherty, and I am a middle-aged biracial woman with shoulder length hair, obviously the picture in the slides was a very old picture, I am -- excuse me -- sitting in a corner of my bedroom in front of a closed door with a lot of various knickknacks, in the background. I want to talk a bit today about the kind of portrayals we've seen, especially people with psychiatric disabilities, and the supports and services that are offered to them in popular culture. And, you know, this really goes back to one of the all-time classic films. One Flew Over the Cuckoo's Nest. And I rewatched it the other day. And if you haven't seen that movie for many years. I would encourage you to watch it again, because there were so many things about that movie that I thought I knew that weren't actually accurate when you watch the movie again, I think a lot of people think about the scene where Jack Nicholson's character receives electroshock therapy or ECT. That certainly was exactly as I remembered it. I had sort of forgotten about the fact that he receives a lobotomy during the movie, and shows up, back on the unit with a scar on his forehead. I had completely forgotten about the scenes of the residents on the ward, playing cards with each other. And the time where he stole the bus and drove them out for a fishing



expedition. These were all things that I just hadn't really thought about. And when I think about my experience. Being a patient in a psychiatric hospital, so much of my recovery. That didn't happen in the hospital, but started there, was due to my interactions with my fellow patients, yes, the professionals were there, they offered a certain level of support they provided medication, some of which I might have been bought a lot of which I didn't. But I knew of nothing else, at that point in time, and I never realized the power that really happened in building relationships with my fellow survivors, former patients, ex patients, current patients. The other film that I think about a lot, and especially because it happens, I am of a certain age. *Girl Interrupted*, was the story of Susanna Kazan, who actually went to McLean Hospital, outside of Boston, which was the same hospital that I was at, um, I'm getting a message that my internet connection is unstable. Hopefully I can hold it together for the next several minutes. But that, again, is a thing where you see the people providing support to each other, and you don't, that doesn't always come through as the main message I think most people think of, oh, the person has to be locked up in a hospital. That's the only way they're going to get better. And it's because of a provision of medical services, which isn't necessarily incredibly person-centered, though some of what I want to talk about today is the fact that, historically, that it has been one size fits all, for people, and not really looking at what the person wants, and I can't wait till later when I get to make a recommendation of an absolutely fantastic film that I had not heard about until two days ago, and really want you to know about it. I watched it last night and it was fabulous. um, the last one that I want to mention just very quickly for lots of different reasons is the *Joker*, because we do see him, we see Arthur at the beginning of the movie. I'm talking to a psychiatric nurse in the public mental health system. Doing that quick check in visit, to make sure that he's been taking his medication, and then being told that there are budget cuts, and that he won't be able to get services. When you think about how especially the supports that are made available to people with psychiatric disabilities in popular culture there very much seems to be one particular model, which is very much medical model oriented. And that is something that I know for myself. I would very much like to see changed because that was a model that did not work



for me and my recovery. And I look forward to hearing from the rest of the panelists and talking more this afternoon. Thank you.

### **Miso Kwak**

This is me so speaking. Thanks Kathy so much for sharing your thoughts on some of the films, and as well as combining that with your personal lived experience. So next up we have Mary, who will be talking to us about the fiction of the supports for people living with dementia as it shows up in our media. So Mary, the floor is yours.

### **Mary Radnofsky**

Thank you, hi, this is a Benji, he is my medical alert dog, and I am a 63-year-old woman living currently with dementia, cognitive disability. Unlike intellectual disabilities which develop in children up to age 18 and stay through adulthood. Dementia begins when you're already an adult. I was diagnosed at age 47 With younger-onset dementia that 16 years ago. But dementia doesn't transform us back into children, not even slowly. Despite media depictions of us misbehaving and needing close supervision, cognitive decline, doesn't turn back time. No matter how much we forget or change, we're still adults with adult experiences. I still live my life in full color as me. I've seen lots of advertisements for assisted-living and nursing homes with dementia floors and been inside them. But my comments today are about their depiction in advertisements and movies, not any one particular nursing home. So here's how they look to me. In a word: "pastel/" Ivory walls, peach drapes, brown carpets, beige sofas, old people in periwinkle, pistachio, pink. Everything watered down and in shades of grey -- as if the paint store ran out of bright colors for people with disabilities, the intended message in the advertisements, is "it's calm here," I get it, but unintended messages come through to some of those messages are "we anticipate our residents may need quieting down", or worse, "residents here are washed out versions of their former selves." I think that's why a lot of us are scared of nursing homes, the fear that will fade into that pastel world. Maybe advertisers don't know any real people with dementia. We're still adults with adult emotions, thoughts, and taste. We're still human, living in color, royal blue, crimson, yellow, chocolate velvet. So when I'm



overwhelmed. I need the full spectrum of medical and social support to get my life back on track, not just as Kathy also mentioned a one size fits all, calming pastel band aid on track is different for each of us. Research tells us that person-centered care helps get us back on track because it's based on the importance of knowing the person behind the patient as a human being with reason will feelings and needs. So we can be an active partner in our own care. Person-Centered Care is implicit in our human rights to the United Nations Convention on the Rights of Persons with Disabilities tells itself. Whatever is important to us. Education, recreation, anything must be understood and implemented through shared decision making with us, not by substituting caregivers' decisions for our own. In other words, no nurse bureaucrat spouse, no one can legally subvert our basic human rights and decide for us. Yet it happens every day in real life, and on film. Take The Father last year's Oscar one to Anthony Hopkins who plays a man with Alzheimer's. His daughter loves him wants him say tolerates his dementia and lets him do whatever. So he fend for himself, but people with dementia lose track of time and purpose quite easily. In the film, no one facilitates meaningful activity for the father, the best he can do is listen to opera alone. Where are the services, adaptive technology, national health care system to help age in place better than with a babysitter or any resource shown to support a man with dementia. That could have precluded the gut-wrenching decision to institutionalize him. I get that the daughter deserves a life, but so does the father, its tolerance, it's all about tolerance. Consider Still Alice, Julianne Moore plays a woman, Alice, whose husband, first in denial. Later tolerates her mistakes becomes resentful than walks out her daughter hesitates to even let Alice hold her newborn baby, until she righteously explains. I know how to hold the baby. Alice's other daughter gives up her studies to tolerate becoming a caregiver, but isn't ever depicted facilitating Alice's decisions. Again, tolerance. Tolerance for our mistakes, tolerance for misplacing things tolerance for cleaning up after our lost body functions tolerance for getting hurt. When we fail to recognize you. In the leisure seeker, Donald Sutherland plays John a man with dementia and Helen Mirren plays his wife, Ella with cancer, they decided to take their camping van on one last venture. Their daughter's response to this decision. "Leave them alone, let them have fun." Tolerance. After many misadventures,



Ella decides. We've had enough fun. She drugs her husband and herself sets the camper on fire and goes to bed one last time. So maybe tolerance isn't enough. Or maybe it's not the best way to show care for and support of people with dementia. But again, that's what's shown in Julie Christie's portrayal in *Away From Her*. She plays Fiona, a woman with dementia who gets lost, skiing, sets the kitchen on fire, and voluntarily enters into a nursing home -- pastel, of course. Her husband visits her dutifully and watches her fall in love with another resident, whose wife discovers the affair and moves him back home. They're all miserable until Fiona's husband devises a scheme to get his wife's lover returned. That's his first real act of person-centered care for his wife. But ironically, it's too late, because he's lost her to another man. What if instead, the husband had provided a ski guide, a cook, a cell phone, or any other accommodation for her disorientation, the same as could have been given the father or Alice, so they too could have had good lives at home. Men many movies have already celebrated overcoming cancer and trauma. So why not also tell the noble stories of people who care for aging parents and kids while themselves battling younger onset dementia, managing Lewy Body hallucinations are thriving with Alzheimer's disease. One such story exists. It's a true story. Orchestra Maestro Zubin Maida recently gave us a PBS special. He invited his old friends. Seiji Ozawa, a former conductor of the Boston Symphony, who has Alzheimer's. To conduct with him in public, one last time. Such a musical collaboration would be marvelous under any circumstances. But this was also a splendid example of humanity and appropriate person-centered care. In concert, made a helped Ozawa engage with professionals who love music, follow an honor him even if he misses a cue, conducting still has meaning to Seiji Ozawa. It's where he fits and still gives him and us great joy, but we usually don't see such person-centered Dementia Care in movies and ads. Why not, why aren't we shown supported in our efforts to live happily, communicating and connecting seeing our wishes come true, standing up for our human rights, maybe most people believe, we don't have any human rights. What if instead of showing pastel rooms with pastel people and pastel lives. A nursing home advertised on send on-site technology experts, they could help with Zoom chats, remind residents of favorite activities reteach us lost skills document our changing interests and perverted means of communication. What





if a person's life with dementia was portrayed as truly worth living, just as much as life with an intellectual disability like Forrest Gump, one film comes close. The Notebook. James Garner, as the older man, provide proves to his wife, played by Gina Rowland that people with dementia can still love and be loved. Yes, sometimes we don't remember the ties that bind us. We know that makes it harder to love us. But as The Notebook proves people with dementia are still fully human, with colorful relationships, unique experiences, ideas, and the ability to evolve. We can still be reached in the present with person-centered care. And maybe some of the past will come back to us. But whether it does or not, we don't have to end up just blending in to pastel wallpaper. Thank you.

### **Miso Kwak**

This is Miso speaking, I'm very thank you so much for providing your critique and reflection on what you hope to see more in popular culture In terms of how we support people living with dementia as well as just the full and rich lives that people with dementia continue to lead with with supports, and many of yeah many supports, and just ways in which that folks continue to strive to be full versions of themselves. So next I will turn to Finn Gardiner, who will be speaking to us about different forms of supports and how they're depicted in the media so, then please go ahead.

### **Finn Gardiner**

Okay, um, so I am a 30 Something bald, black man wearing glasses, and I'm lying forward in my on my, my bed with next to my cat, who is blurred out so she's not on the screen, and I'm wearing a purple polo shirt. So, I'm gonna be talking about informal person, informal and formal person-centered supports, and a few specific media portrayals. And I'm also gonna be talking about how they're often stereotypes about, about people who receive support for a disability and how these portrayals counteract those stereotypes. So, both the first two portrayals I'm going to talk about are their bio pics are based on real life story so they're going to be a bit different from what Mary was talking about. So the first the first portrayal is A Beautiful Mind which was both a book and a movie about the mathematician John Nash, who was an important theorist of the 20th century



and early 21st century as well he died a few years back. And when he was right in the middle, during the prime of his career, he developed schizophrenia and started having hallucinations, he started having trouble perceiving reality as the rest of us see it, and he needed to stop working and he received support, and he received support and his, and he also. And those supports came in several ways. He checked into McLean, like Susanna Kazan, and he also received support from his parents and his wife, um, well and he and his wife broke up, but she's even, even then, she still provided support to him alongside his his parents and he, um Nash eventually recovered and commentator said that if Nash had not had those person-centered support, if he had not had his parents, his colleagues his ex-wife, and all these other people supporting him he would not have recovered, and that kind of ties into what Mary was saying about portraying those supports. On in movies and TV shows and an ads, and other popular media, how do we show people recovering, how do we show them doing well. How do we show them how do we show them getting help from their friends from their family from their community doesn't necessarily have to be a formal support system even though Nash did go to McLean. But it wasn't just McLean, that helped him get better it was, it was being around family and friends and colleagues who cared about him who made sure that he was able to do things that he enjoyed that he was able to be treated like a person, as an autonomous human being, even while he was suffering, even while he was struggling with, with his, with his schizophrenia. And, and, and the situation with John Nash, also sheds light on another on another. I guess it's another it counteracts another stereotype that we often encounter about people with disabilities who need extensive support. There's this idea that if you have extensive support needs you, like if you have extensive support needs you must also have an intellectual disability, or the converse the opposite, in which people. People get denied for services because of a score on an IQ test whether it's too high or too low, and support needs, do not depend on someone's intellectual ability. You can be like Nash you can be absolutely brilliant you could solve important mathematical problems you could discover the cure for COVID-19 You could do all kinds of things but you may still need help cleaning up your house, you may still need help getting your groceries done, you may still need help navigating some of the issues of everyday life,



even though you're good at doing math or reading or doing epidemiology or being a literary critic or any other, or any other intellectually demanding line of work, you can be good at all those things but still need help people do not people do not have uniform abilities, but so many media portrayals so many, I guess, so many ingrain, there are so many ingrained stereotypes out there that if you have high support needs, then you must be incapable of everything and that is not the case. And so that leads me to the next portrayal. So, Stephen Hawking, the astrophysicist, he bit. He's had a few films made about him, but I'm gonna talk about The Theory of Everything which came out about six years ago. And a large part of the movie depict his relationship with his first and second wives, and how they support him, consistently, after he develops, um, you know, after he develops ALS motor neuron disease and amyotrophic lateral sclerosis -- so he's, you know loses a lot of his mobility, he's not able to control his body the way that he was before he's not able to talk anymore, so he's also an example somebody who uses alternative communication so that's, that's another example of person-centered support. He has a -- he has, um, he has a device that he can use to communicate his ideas even though he can't talk anymore, or right, I don't, I don't think he could write by hand, either he was still able to communicate what he needed to communicate because he had those supports. And he was surrounded by people, his, his wife, his daughter, his both his wives and his daughter and his colleagues and so on, so he was still able to make all these he was able to do his research with ALS, he's living with ALS for about 50 years, because he had that help because he had this community around him, because he, um, people did not write him off because he had ALS. They did not say, oh, you can't do research anymore Steven because you like, you know you Dr. Hawking cannot do research anymore because you're sick, because you have ALS. He was still eight, but that wasn't true, because, although he had physical disabilities. And although he had neurologic, it was a physical neurological disability. He was still able to do his job. And a lot of people think that oh you have a disability, you can't work. We have a disability, you can't do anything you have a disability, you just get to go in a nursing home and stay there, and languish and let that pastel nursing home that Mary talked about, you're just stuck in that pastel nursing home for decades, because nobody thought, oh wait,



you might still be interested in things, you might still be able to do your job. But you might have to do it differently, you might have to get somebody to help you communicate you might have to get an iPad or something to help them talk, you might need to use a spelling. You might need to use like a letter board or some other communication device or you might have to get a personal care attendant, you have to, you might have to get somebody else to help, but that doesn't mean that you're incapable and though we're not all you know I am definitely not an astrophysicist, but, you know, even in my own life. There are things I can do my job pretty well, but I also need help with my help with executive functioning with getting certain day to day tasks done. But I don't always get. And I don't always get that help because I don't because I kind of fall through, I kind of fell through the cracks when it comes to the service system where I don't qualify for anything but I am also not a fabulously rich scientist who can afford to hire nurses or other supporters. Um, and finally this is kind of an offbeat. I guess kind of an offbeat interpretation, but, um, but there is also the TV show *The Good Place* and although that doesn't really seem like an example of person-centered supports on the surface. We can argue that Janet, who is this all-knowing, almost like all knowing, all powerful, sort of cosmic assistant. She ends up providing support to all to the human characters by feeding them by, and by providing personalized care for everyone who makes a request. And so that's another example of person-centered supports. And what's really interesting about this one it's it's an example of people receiving those kinds of supports, without necessarily being disabled. Now we can argue that some of them had psychiatric disabilities. I think quite a few of them did, to be honest with all the trauma that they went through, you can argue that some of them may have had PTSD or anxiety, I'm pretty sure Chidi had anxiety, but, um, that's an example another example of how personal personalized supports are depicted on in popular culture, you may not think of it immediately but honestly I think a lot of the reason why we don't see many portrayals of these kinds of supports, or that is that we don't necessarily think of them as a solid thing, we think of them as separate things. Oh, getting a nurse, or getting help with communication, somebody cooking for me. Some, they just think of it as help, person centered planning that's definitely a term that is mostly confined to the policy world. So, I think that there may be more portrayals than



you think it's just because we use all these buzzwords because we have all this jargon and can't in our in policy land, we may not see it because we're thinking of it as the solid group of activities, whereas other people may just be seeing them as cooking and cleaning and taking somebody to the hospital.

### **Miso Kwak**

This is Miso speaking Finn, thank you for your such insights on how there are so many different forms of supports and that supports are really for everyone, not just for folks who are maybe labeled as having certain, you know conditions or disability. So, yeah. Finally, we have Andy next, and he will be talking to us about topics such as independence and intersectionality and how they show up in person-centered supports the fiction depiction and media, so Andy.

### **Andy Arias**

Hi everyone, I'm so happy to be here. I'm sure everyone can hear me [clears throat] -- and I suddenly got a frog in my throat which is amazing way to start the presentation. I am so honored to be here with a group of wonderful people, with such an array of experience. So a little bit about me, I would say is that, you know, I grew up in systemic poverty, and I grew up in the foster care system. So the system of services and supports for me we're very sporadic, and we're very against the grain of like you're able to do certain things you're able to accomplish whatever you want to that was the complete opposite that was taught to me, it was like, "you're not going to be able to get a job, you're not going to be able to, you know, live on your own drive a car go to college, you know have a family" and all but one of those things, I've already done, I do not have a child yet, but that is something I'm already planning to do in the very near future. But one of the, some of the things I wanted to touch on today, were some of the recent depictions of disability in the media and how services and support are lacking from those narratives, but also the, the lack of BIPOC, or the lack of color of individuals within those narratives. And the three shows that I sort of want to touch on, are Speechless, and Special, and the other one is escaping me right now and I wrote it down so I'm going to go back to my notes and view it... It's Speechless, Special, and The Good Doctor, are the three that I want to touch on



really briefly. So, you see many different aspects of -- in the Good Doctor, of a doctor with autism, achieving great wonderful things. Now, I know, Freddie does not have a actual disability, but that show is working on casting authentic portrayals of disabilities, even though the main actor doesn't have one. So, I think, honestly, the portrayal of disability in that show is a very good one. But, what I find lacking is, how did he get there, how did he become the doctor, right what services and supports, other than someone taking them under their wing and saying "you can be a doctor," how did you get there, you must have had support in school. Um, you must have had supports throughout your lifespan to teach you how to get there, and it just glosses over that right, it shows that sort of familiar familial support from his brother, and the Doctor who, sort of, shuffles him through whatever system he came from, and puts him in the hospital, through his education, and his talents. And the other one that I want to talk about again is Special, which is a new show that came out on Netflix, a couple years ago with my friend Ryan O'Connell, which is a great narrative of what disability and LGBTQ looks like in today's world, again, they gloss over, none of the services and supports, it took for Ryan to get to employment, right, or to get to where he's at, or any kind of assistive technology, that he may or may not use in order to be an independent person, again they rely on the strong familial ties, of the mother and the son, moving together to get him to independence, which again is great, but not everybody in our society as we know, has those familial ties of services and support. So what happens? They end up in skilled nursing homes, or group homes, which I find, you know, to be a, you know fancier nursing home, but it is, you know, group homes, and those kind of systems aren't meant for you to like get out and become independent, they have no way of giving you that extra boost to be that. And when I lived in group homes or state hospital when I was younger, when I would always ask, "How can I be more independent?" "How can I choose to to transition out?" they were like, "Well, you're not going to be able to do that." So the systems we have now, are, are a little wonky right we can say this, honestly, but we don't see them in the media, should we have no way of educating the larger masses of how these function, and where they're broken and how they can be fixed. The other, the other show that I wanted to talk about is Speechless. Again that show came out, you know, a few years ago and it was



a great funny show, and it did show a different care of, you know, disability, and economic stability, right, that family was poor, that family dynamic was, again, the son and the mother, pushing through adversity together and eventually you see the individual achieving independence. Oh but wait, you don't really see that you hear it talked about, because he gets accepted to New York University, but you don't see how or why you just see him, overcoming the aspect of of his disability in a way where it's, it's perceived that he's going to achieve no matter what. Now, I think that's a disservice to our communities. For those with physical disabilities or intellectual disabilities. I myself have CP, so I sit on 24-inch rims at least 12 hours a day. Yes, I transfer, but I have no qualms in saying what services and supports, I needed to get here, to where I'm at. Actually, I did the opposite and my services and support, were, were short of, I had to push away from them, in order to maintain my independence, but I also wanted to touch on really quick thing. I know we're running out of time. The fact that these portrayals are mainly are predominantly of white individuals, and we don't see individuals of color in those portrayals I'm Latinx and you know I've never seen myself on television, as somebody with a disability. I've never seen a achieving African American with a disability on network TV -- Latinx, And so, also. But they are very different experiences. Right. And they view disability in a very different way they view the trust of the systems and services in a very different ways. So, even though we're seeing those things in the media of the good doctor, and speechless and special and they seem to be achieving this perceived independence. We need to know how they get there, and we need to know other ways of getting there for BIPOC communities, those who are like Latin x, or for those who are in the black or Asian communities we need to see other aspects of disability and races, achieving those same goals and how they got there. Thank you.

### **Miso Kwak**

This is, this is Miso speaking, Andy, thanks so much for putting your remarks together, to you know talk about how. Yeah, the media needs to do better in depicting various aspects of system and support as well as more representation of communities of color. And, yeah, definitely a more authentic representation of disability experience as well. So that concludes the part of the webinar where



each speaker will share their remarks, and we're going to transition to a panel portion, and in which I will pose a question to the panel, and have panelists speak to these questions. So first question that we have here is that, you know so far in our webinar today, we've talked about in ways which there are shortcomings, to the picture of Person Centered supports and popular culture. And I will so I would love to hear your thoughts on how we might make progress to do a better job of depicting persons, person centered supports and pop culture, Kathy, I would love for you to take the stage first.

### **Kathy Flaherty**

You might not get me on video because I can't This is Kathy, I can't restart my video, but I also have enough issues with my internet that maybe you'll hear a sound. Even if you can't see me. I know for, for me personally, and a lot of people. I can't help but wonder, as we get more actually disabled people in the industry behind the cameras in front of the cameras in the writing rooms, because so many of the stories have been taught that have been told, or they written by abled people for abled people, even if they're telling the stories of a person with a disability, And it's true in terms of what I've heard my co panelists talk about, you know, I will never get out of my head marry saying everything passed out, instead of a full array of color, um, you know what Finn said, do they show people the process of recovery, and what Andy was saying about the whole diversity of experience so my hope would be is that as we get more people with disabilities, telling our stories for us, as opposed to trying to sell our stories to the community of people without disabilities that maybe we'll see more genuine portrayals.

### **Miso Kwak**

And this is me so thanks for that response Kathy. Any other panelists would like. If you would like to speak to this question, please chime in.

### **Andy Arias**

I would say just really quickly I agree with everything that Kathy said, I think if people with disabilities are going to be able to tell their stories in the writing room





and in the casting room. Then you'll get diversity, and then you'll get those individuals, authentically portraying telling their own stories.

### **Miso Kwak**

Great, um, Andy. Thanks for the comment, and this is Miso again. Yeah, that's I think that's a good segue to the next question that we have on deck, you know, Andy. You're someone, quote unquote, "in the industry" -- among the panelists, right. So, um, we would love to hear your thoughts on, you know, what do you think are some of the ways, or what are the ways that you are, you know, working in your work in the positions that you hold and projects that you're working on to, you know, bring more authentic and diverse depictions of person-centered supports. Yeah, so could you speak about that.

### **Andy Arias**

Yes, definitely. So, I've been a producer and an actor and a stand-up comedian for over a decade, and you know when I go to castings, now they're looking for authentic ethnicities of disability, not just ethnically ambiguous -- which means "can you play white", which used to be five years ago. That's what casting directors would say, but in my current work, of what I'm producing, because honestly, you have to make, you have to make your own work. If you want to be a successful person in the industry with a disability, you can't just rely on casting and producers to do it for you, especially if you're a unicorn like me, it's just not going to happen so I'm producing a film called Danny's twins right now which will be out in the next few months, and it's about my friend, Danny in Virginia who had twins during COVID She's a complete quad. And so, we're telling that narrative of what services and support she needs. What does taking care of a child or twins look like when you're completely quadriplegic, where the family support, sure, but what other services does she have what other services is she lacking because insurance doesn't cover those things -- or what she has, because of her privilege. So we cover all of that in a short, 40-minute film, because we want people to know the "real" of it. Right, we want people to know about the discrimination, and the positive, that is happening in our current world.

**Miso Kwak**

Sounds great. Andy, this is me so again I'm really looking forward to checking out that film. So, Bevin husband, sharing the links to various films that have been mentioned so far. And when we send out the list as a resource, after the webinar we'll be sure to include the film that you're working on Andy. So let's go on to next questions, and that is what do you see as implications for better depiction of person-centered supports and popular, popular culture. I'm Finn, would you like to go.

**Finn Gardiner**

Okay, I think that if we do have better depictions of the kinds of help that people need to live in the community, as people with disabilities or older adults, then I think that's going to let people know that those are options, that's going to let I'm seeing that is going to let people know that they can advocate change within different systems to ensure that they get that kind of help. For example, if someone sees that, oh, I don't have to go to a nursing home, I can get help from a personal care attendant, they may be able to fight for that they may be able to recognize that hey, I can get help, I can get. I can get the support I need to live to thrive in the community, without having to go into a nursing home. I also think that there's room for possibilities that can be expressed through, through the media, ideas that may not exist yet. In real life, but ones that policymakers can look at. Because, when, when we're creating popular media when we're created when we're writing books or writing TV shows or movies, we get to tell new stories, we don't have to tell the same old story we've heard all the time we get to change that. And we can do that with, um, with support that actually puts the person with a disability first, but actually puts the older person first, as opposed to this Um As Kathy said earlier this one size fit fits all model, that's more like one size fits none right or maybe one size fits a few, maybe, um, but if we can, but if we put those ideas on TV or in a book or on a YouTube channel or any other media, then those could those could, I think those could, um, kind of light the fire under people's rear ends to make some change.

**Miso Kwak**



Great remarks, Finn, I agree with you. And the other panelists would like to chime in for this question. I'm hearing none, this is Miso speaking, um, we'll go to next question, and that is any advice on how those of us who may not be directly involved in this industry of creating, you know, popular media: How can we become more critical consumers of popular culture, in thinking about how suppers for people with disabilities are portrayed? Mary I would love to hear from you.

### **Mary Radnofsky**

Oh, Okay, well, all I can tell you is what works for me. I look at events or shows and ideas through a human-rights filter. That helps me see if people are being listened to, treated fairly and respectfully. The way I dealt with my mom who was diagnosed with dementia only two years before I was. And the way I'd like to be treated. No matter my illness, my accident or cognitive loss. I can never be any less human. That's why the Human Rights filter works for me, cognition, my cognitive abilities is not the only aspect of my existence, it's not what defines me only. A few years ago I wrote a brief declaration of my human rights, and it just takes about 30 seconds, let me read it to you if I can. [reading] "I am, and shall always be a unique person with human rights, equal to yours. I'm also part of humanity, the collection of all people, who ever lived, are here now, And will ever exist. At times we assemble to create a whole greater than the sum of its parts. Yet we each maintain our individuality. At times, I must stand alone may be far away, But I'm still human. Once human, forever human." That sums it up for me. Thank you, Mary. Yeah, that's super powerful.

### **Andy Arias**

I'd like to chime in real quick.

### **Miso Kwak**

Please, go ahead, Andy.

### **Andy Arias**



I also think that media is changing, right, so now we have social media which is a huge platform and we have these platforms that you don't even need cable anymore you have Hulu you have Netflix you have Disney plus all of these things and all those services, asked for feedback from media through Twitter, through other aspects so if there's a show you really like or dislike, there's a way for the consumer to make their voices heard. Every popular show does Twitter chats where you can then communicate with the show, and let them know this works for us, this doesn't work for us. So just because they're depicting a character with a disability doesn't mean you have to agree, and you could always let your voice be heard and say to that team that's doing those chats, "hey, this is not right." I do it all the time. I have tweeted so many shows and so many producers, saying you should fix that narrative because the narrative is not true anymore, And it works I've gotten great feedback from that.

**Miso Kwak**

This is Miso, yeah and yeah I think that's a great reminder and for everyone here for, you know here. And I'm sure we all you know enjoy watching shows and movies. At least now and then right so thanks for that, um,

**Mary Radnofsky**

me, so I'd like to respond to that, this is Mary,

**Miso Kwak**

Please go ahead.

**Mary Radnofsky**

Um, I think it's also a brilliant idea for another reason. I think it also shows that we do have control, we do have power over our lives. If we take advantage of it. I think when we talk about consuming pop culture, or watching a show on TV or going to the movies. I think we forget how passive, an experience that actually is. And Andy brings up a really good point, which is we can actually engage in the creation of the narrative now, and sometimes it's after the physical production of



the film or the movie, but that's not where the narrative in the global sense ends, the narrative about a story is actually what is the truth that people remember, it's often not as Kathy even mentioned what you really remember. But it's the narrative that we have constructed around it that matters and that lasts.

### **Kathy Flaherty**

This is Kathy I just would want to chime in on that. I think about how, you know, the recent movie *The Guardian*, or *I Care A Lot*, that's the one. I remember live tweeting that movie, as I was watching it, one night, because it was making me so upset as I was consuming it. And thinking how some things were portrayed for entertainment purposes, but also represented the real life experiences of so many of my clients and I, and I had to for myself, I think, to maintain my own sanity while I was watching that movie, do that. Um, and I think, you know, that's why, thinking of the, all the documentaries, and short films about the situation that's going on with Britney Spears, the same thing, You know yes this is a celebrity, who has been subjected to conservatorship, which is certainly not a person-centered planning and support but a lot of people are subjected to it, and how so many people are using that as a springboard to have a larger conversation about what systems should look like.

### **Miso Kwak**

This is Miso, um, yes. Great points from both of us, so thank you. And, yeah, it just reminds me how NCAPPS community we often talk about advocating for ourselves in our community. So I think it's no different when it comes to consuming popular culture, and providing our input to, and, you know, continuing the that narrative. So, this will be the last prepared question for our panelists, and that is, for each panelist, um quickly I would love for you to just give a shout out to, you know, film , or some piece of media that you recommend for our attendees to check out, and that, you know, that depicts of Person Centered supports well. So let's start with you, Finn.

### **Finn Gardiner**



Okay, so I'd like to recommend one of the films that I mentioned in an earlier so I'm a theory of everything. The Theory of Everything I really liked that one.

**Miso Kwak**

Mary?

**Mary Radnofsky**

I'm actually going to deviate from the question slightly because I can't think of something that depicts things so well that, you know, it's worth mentioning, but I imagine that each one of my fellow panelists, and most of the people right now on the call, live in a community where they like or love the people they live with, it's in the best place they can afford. And they're with friends or family, they have stuff that gives them pleasure. So you fit somewhere. And I believe as Andy mentioned, there are some people who have helped get you there. You get to do a job and fulfill a role that makes you relevant to society. You're living examples of person-centered care and support. All you have to do now is look a little closer at who's been providing it. And it may not be who you think. So ask them how they do it, watch them do it maybe thank them and pay it forward. That's all.

**Miso Kwak**

Thank you, Mary. Kathy, how about you?

**Kathy Flaherty**

This is a movie that I watched last night, and it actually is an absolutely fabulous description of our depiction of person-centered supports and how a whole community support somebody, and it's called Lars and the Real Girl. And it stars Ryan Gosling. And at first you're like this doesn't make sense. He has a delusion, he thinks that this sex doll is a real woman. And that could have gone so horribly wrong, but it actually didn't, because it showed things like his brother and sister in law, going to their church and saying, "he thinks this is real, it will really help if you other people who he loves and respects, treat her as real." And then what happens is the whole community does treat her as real. And then you see him interacting with people in a way he just didn't. Um, and then the movie just ends



really quietly with him holding hands with a co worker, which was something he had never done before, and it was just, it was amazing and I'm so it's Lars and the Real Girl, I would definitely highly recommend that movie, it was very good.

**Miso Kwak**

Thanks, Kathy. I would love to watch the show, watch that movie too. Andy, how about you?

**Andy Arias**

Hi, I'm gonna deviate like Mary and say that I don't see the portrayals that I want to see with services and supports yet. Now, I think Danny's twins the film that I'm going to be releasing soon does do that a little bit and I can say, I can say without giving away any NDA information that all my current stuff that I'm going to be working on does have aspects of services and supports, woven in there, authentically so stay tuned 2021 and 2022 for that.

**Miso Kwak**

Sounds great, Andy, I'm really excited to follow your work and support your work. So that concludes a panel portion and I'll be handing it over to my colleague Bevin and we'll be moderating the Q&A portion if there has any that come through the chat. If. And I just want to say it's been a great joy and honor to be moderating this panel, and yeah, so thank you for letting me do that and also I want to give a shout out to my colleague Connor who brought up this idea in the very beginning to do this webinar so thanks everyone. And let's hear from Bevin now.

**Bevin Croft**

Thank you, Miso we're so proud to have you as an NCAPPS moderator, and thanks to our panel for this discussion. Thanks also to folks who are keeping chat poppin. I've really enjoyed checking out your recommendations and the discussions that you've been having on the side, and a few folks have asked if we'll be compiling all the film references and recommendations, the answer is yes, we will. We'll make a compilation of films that were both films that were



referenced in the discussion but also in particular will highlight the recommended films, and Andy will do our best to keep current on all the stuff that you're producing so we can keep the recommendations current as well. All right, if you have questions for the panelists, you can go ahead and drop them into chat, and I have a few quickies. While folks are doing that. The first is an easy one, if you could if you have social media handles a Twitter. Twitter handle, if you're active on any social media or if you have a website, to all of our panelists if you could either share those in chat, or, or you can share them verbally, whatever, whatever you like. And Kathy you already shared yours I believe you're at @ConnConnection on Twitter. Yeah. Okay, great. and I see Finn has shared twitter handle at @PhineasFrogg. Andy's website is in chat. And while you're at it, please do follow NCAPPS on Twitter @personcentering. Okay. and if you have any other social media handles. Go ahead and type them in and we'll make sure they get out to everyone. Another question is, we've, we've centered the discussion primarily around fiction and depictions of. In, in the fiction in TV and film and fictional film. Does anyone have any documentary films that come to mind when you're thinking about depictions of Person Centered supports? I'll open that up to the panel. And I will say in chat already crip camp. The documentary that was nominated for an Oscar and a very well acclaimed has been referenced in chat. Any other documentaries to either recommend or critique?

### **Mary Radnofsky**

This is Mary. There's a documentary that has been in process for the last couple of years being made by a private company, it's going to be called Susan's story. It's the story of Susan session, who had frontotemporal dementia, and then he was doing some work with advocating for the rights of people with disabilities. Unfortunately she then developed cancer and died. Fairly recently but she was the most remarkable advocate, and I hope that the story does eventually get finished. There are excerpts that you can see from it online, I believe there's a Facebook page, just called Susan's Story. And again, her name was Susan Session and it is a beautiful story.



**Bevin Croft**

Thanks, Mary. Any other documentaries to reference? And more are coming into chat which is awesome. Um, so, um, and films, please do also share any films and chat I saw someone referenced Diving Bell and the Butterfly that's one that we talked about a bit when we were planning this, this webinar. Um, another, another series of comments in chat was really sort of remarking on, you know, we've we have focused, as we do on, you know, the depiction of services and supports for people with disabilities for older adults with long term service and support needs, but there's also the depiction of the communities around them, and the people who care for them, thinking about both paid, caregivers, and an unpaid caregivers who are often family. So, we've had some reflections from from in chat on this but I wonder if anyone on the panel would like to talk about your remark or reflect on from the, from the caregiver perspective, what are you seeing in terms of depictions of sports or lack thereof. I know some of you have, have been both in caregiving roles and, and have received care.

**Andy Arias**

I mean there's, there's a huge lack, I think of, of PA or, you know, personal attendant, images, my friend Angela Rockwood who produced the first reality TV show with girls in wheelchairs called Push Girls, won a Critics Choice Awards about six, seven years ago. And one of the things that they were like, "oh don't show that" was her lack of nursing care that she needs to be an independent person. Right, but that wasn't sexy enough for TV, and I was like that's such a disservice, because now she's still having that struggle of getting the nursing care that she needs just to get her cell phone out of bed and to live like a normal life. And so there still needs to be that narrative of like yes, if you work, you're going to have to have the services and supports to get you there if you don't work, you still need those services and support, and how do you get those successfully and not have to struggle every day because getting those supports is sometimes a full time job.

**Bevin Croft**



Any others would would like to remark on the depictions of caregivers have caregiver perspectives. Okay, so I'm looking at chat, and I'm seeing a flood of resources, and of ideas coming in, someone noted that YouTube is actually a good place to find media, maybe media that doesn't make it into mainstream. I think what I'd like to do is just turn things back over to each of you if you have any final words that you'd like to share before we wrap up today. And maybe I'll start with, with you, Finn.

### **Finn Gardiner**

Okay, so, we've had a wonderful conversation today about the importance of representing the kinds of help that we all need to live in the community. And I want to remind people that it's important to look beyond the stereotypes, it's important to stop thinking of community supports as as just medicalized supports. We need to stop thinking of the kinds of support that people get as buzzwords, we need to think about them as real concrete, real concrete kinds of help that people are getting from their friends from their families, from their neighbors from their communities from advocates, because we are all interdependent. And whether we have a disability or not. And the kinds of support that people get as people with disabilities who are living in the community. That's just another reflection of our interdependence. And so, it helps not to think of these things as isolated, they're not all sealed up in this corner. They're part of people's lives and we have to remember that we're talking about living, breathing, people.

### **Alixé Bonardi**

Thanks, Cathy, closing remarks from you.

### **Kathy Flaherty**

I would just say, and this was something that somebody in the chat mentioned, we've got a bill out there The Better Care, Better Jobs Act that would increase the ability, you know, the availability of home and community, community based services so while it's been, I've loved everything about this discussion, and even having had, you know, pre discussions before the webinars where people just amazed at the wisdom, and frankly the poetry of what people said today, but just



remember there's something out there that could really change a lot of people's lives so don't forget to take that with you, and you know heed that call to action of advocating for that bill.

**Bevin Croft**

Thank you Kathy, speaking of poetry, Mary I'm still reeling from your statement on human rights. So thank you for that, for me, I'd like to hear your closing remarks next,

**Mary Radnofsky**

Oh, well , I would. I would echo something that I said several minutes ago. Because it's a, I think there, it touches upon the many aspects of who we are as people. We are defined legally, and spiritually, and socially and familial-ly. But what ends up becoming the way that people define us, is so often by our disability. And, in my case, cognition, even though I'm in a progressively losing battle here, it's not the only aspect of my existence. And to be able to look at me and my colleagues in a way that is not just medical, and you're right we don't just need medicalized support and the support that we've gotten from the time we were children, up until the time we're adults comes in all sorts of different forms from all sorts of different people, even if it's only a moment. Passing somebody in the street that sees us for us and says hello or helps us or smiles, those are forms of support, and they humanize us. And that's why this human rights perspective, seems to work best, at least for me. So that's what I would encourage people to look for.

**Bevin Croft**

Thank you, Mary. And Andy I'll give you the last word in the just one minute that we have left.

**Andy Arias**

Yes, I will be quick. Social media is a huge platform, and the post ADA generation is loud on social media, they're all over Instagram, Tik Tok, Facebook they are the influencers of the next generation. So pay attention to those



individuals because that's going to shape the future of the disability rights movement, not to say that we cannot all collaborate, but there are voices out there, they just need to be held up higher. And so that way, diverse communities can have their voices be heard to

**Bevin Croft**

Thank you Andy, Kathy, Finn, Mary for this for this discussion, and thank you me so for, for putting all of this together. I've learned so much from all of you. This concludes the webinar, Connor if you could please put up the evaluation questions if you have just a moment before you go. If you could click through the seven questions in the webinar evaluation, we use your responses to improve our monthly webinars, everyone who's on here will be subscribed to our mailing list, it's just a couple emails a month and we'll let you know when the recording and when the resources list is posted. And we'll look forward to seeing you again in future webinars in September and October. Take good care everyone have a great afternoon or morning depending on where you are. And thanks very much!