# Disability Deep Dive Episode 99: Enough is Enough: The Crisis of Preventable Deaths in Learning Disabilities

**Jodi Beckstine** (00:14):

What happens when society knows how to prevent harm but refuses to act? What does it mean when people with intellectual disabilities are still dying too soon from causes we know how to stop? Today, we're taking a hard look at why these preventable deaths keep happening and what it takes to push for real change.

**Keith Casebonne** (00:37):

Hello listeners and viewers. Thanks for joining us. I'm Keith.

**Jodi Beckstine** (00:41):

And I'm Jodi. Welcome back to Disability Deep Dive.

**Keith Casebonne** (00:44):

Today's episode is Enough is Enough: The Crisis of Preventable Deaths and Intellectual Disabilities. Our guest is UK Professor Sara Ryan, a fierce advocate researcher and author of the new book, Critical Health and Learning Disabilities: An Exploration of Erasure and Social Murder.

**Jodi Beckstine** (01:00):

We talk with Dr. Ryan about the reality behind the headlines, the stories and systems that make it possible for people with intellectual disabilities to die early, even when the problems and the solutions are well known. She lays out why an action isn't just neglect, but a pattern of harm that's hidden in plain sight.

**Keith Casebonne** (01:18):

You'll hear about the difference between the UK's term of learning disability and the US's intellectual disability, why these deaths continue despite decades of advocacy, and what it takes to move from outrage to action in both policy and everyday life.

**Jodi Beckstine** (01:33):

And after the interview, stick around for our deep cut. This week, we're diving into When Barbara met Alan, the BBC drama about the UK's fight for disability rights and the grassroots movement that led to the Disability Discrimination Act. We'll talk about how it compares to the Americans with Disabilities Act and what both mean for the future of disability rights.

**Keith Casebonne** (01:53):

Let's get into it.

**Jodi Beckstine** (01:56):

Hello and welcome to Disability Deep Dive, Professor Ryan. Your book, Critical Health and Learning Disabilities: An Exploration of Erasure and Social Murder focuses on people with learning disabilities, which in the UK means what Americans call intellectual disabilities. Can you start by introducing yourself and sharing what led you to write the book?

**Sara Ryan** (02:16):

Yeah. So my name's Sara, and I'm a professor of social care at Manchester Metropolitan University, which is in the north of England. And my research since early 2000s has focused on people with learning disabilities and autistic people. And I did have a son with learning disabilities who died in 2013, and carried on researching in this area and writing in this area. And then I was asked to write a book about health inequalities and learning disabilities. And so I started to write the book, but the more I read, the more I was drawn to the idea that people with learning disabilities are being socially murdered. And once I sort of reached that point, which was not the book I'd been commissioned to write, I couldn't really leave it because the whole point is this idea of social murder is that if you know the conditions that lead to the preventable and premature deaths of people and you do nothing about them, that is called social murder.

(03:22):

And as I was reading more, and I knew a lot of this anyway, but we know in the UK, people with learning disabilities are dying 20 to 30 years before their non-disabled peers on average. I mean, this has been documented over and over and over again. And we have had inquiries, safeguarding reports. We've had so much research into this, you would have to be walking around with a blindfold on not to know this, and yet nothing is done to change it.

**Keith Casebonne** (03:53):

Yeah. It's a very strong term. We were both... It's definitely an eyebrow raising to hear the reference of social murder. But it sounds like as you're putting it's a very apt term. So you've kind of explained what the term already means, but can you dive in a little bit deeper into the meaning of that, the implications, and why you felt it was the right and important term to use in this case?

**Sara Ryan** (04:27):

Yeah. Because there's such strong evidence to tell us... I mean, if you've got a learning disability, you're not ill. It's not a medical diagnosis, it's a label basically that you're failing on certain aspects that are held to be important, so called intelligence or being able to rationalize things in a way that people understand or recognize. And so the fact that we've got a certain group of people who repeatedly die young led me to go back to Engels who wrote The Conditions, The History of the Working Class. I can't remember what it's called now, The History of the English Working Class, and he argued this in relation to the working class people in England in 1845 that you know why people are dying and you're not doing anything about it. Once I'd sort of reached that point, Engels says it's not deliberate, it's more through a mission than commission. This is Engels' argument, that the conditions are there, we're not doing anything about it.

(05:30):

But the more I read, I was sort of thinking, is this really not... I wouldn't go as far as to say it's deliberate that people are setting out to murder people, but there's no engagement with this. There must be a sort of barrier of bystanders who see unacceptable, totally unacceptable treatment of people despite human rights frameworks, despite legislation, despite so many processes in place, safeguarding processes, regulatory processes, all those are just sort of swept aside when somebody with a learning disability unexpectedly dies.

(06:07):

And we saw this last week, there was an inquest into a young man, I think he was 17, who died. He had Down syndrome and he was taken to A&E by his parents who said he's clearly not very well. And the first doctor looked at him and thought he looks all right to me. And they didn't do blood tests because they thought that the young man would just sort of kick up against the blood test. And so they told him to come back to A&E the next day. So he went back to A&E and the second doctor looked at him thought well, he looks all right to me, and didn't do the blood tests. And said, "But you have to have the blood tests in the community because he wouldn't respond well in hospital." So by the time he got back home, he was too unwell to go to the GP to have a blood test to find out why he was ill. And so the GP visited him at home, fair enough, but she looked at him in bed and said, "Well, he looks all right to me. " This young man was dead within 12 hours of that visit.

**Keith Casebonne** (06:57):

Oh, wow. Geez.

**Sara Ryan** (06:59):

And last week, the coroner, the coronial system, which is supposed to get to the bottom of how people die and why people die, decided that it was natural causes because he'd looked all right. The coroner sided with the three medics who'd seen this boy instead of the expert witness who sort of said... This is the thing that coats this area, is absurdity. And the expert witness gave testimony to sort of say, "You might have thought he looked all right, but he clearly wasn't because he died."

**Keith Casebonne** (07:29):

Oh wow.

**Jodi Beckstine** (07:29):

Wow.

**Sara Ryan** (07:29):

And you sort of think, well, that's sense, isn't it? That obviously he wasn't well, he wasn't given healthcare to keep him alive. And yet, we have a coroner putting on public record, "Well, this young man died of natural causes."

**Jodi Beckstine** (07:43):

Wow.

**Sara Ryan** (07:46):

Yeah.

**Jodi Beckstine** (07:47):

Yeah. That story really drives that term home for what you're talking about. You've pointed out that there's already research and recommendations out there, but not much is changing. What action do you think is missing when the solutions are so clear?

**Sara Ryan** (08:11):

Yeah. That's such a good question because I argue that we do know what should change because the recommendations have been made over and over and over again. And it's not difficult, it's basically listen to people, respect people, and treat people as human beings. And yet, there's this resistance to doing this. So in the book, I identify this collective of people, which is a very loose grouping of professionals, social care professionals, policymakers, politicians, commissioners of services, all sorts of people are in this sort of collective where they're not noticing or they're refusing to notice what's happening. And that's the big puzzle is how could you not notice when we have all the evidence?

**Jodi Beckstine** (08:59):

Right.

**Keith Casebonne** (09:01):

Wow. Wow. Well, you've written that people with learning disabilities are often not seen as fully human. Again, you've mentioned that they're not seen as equal essentially in both healthcare and society. Can you tell us a little bit more about how this shows up in real life? I mean, you just gave us a wonderful example of something that just recently happened, but other ways that this shows up and why it just keeps continuing.

**Sara Ryan** (09:33):

It sort of shows up in everyday practices where you don't see people with learning disabilities out and about in the way you see other people. People are often in day centers or they're segregated. They're living in a supported home with four or five other people with learning disabilities and there isn't the staff or the will to take people out and enjoy themselves. So it shows up in that way. And I sort of find that if people mingle more to everybody, if everybody mingled more, these problems would reduce because you would see each other as human. And then you would have that outrage to sort of say, "You can't do that because that's clearly wrong." But if you don't mingle with certain people and then you have this distance, that means people are scared of you or they don't understand you or they think that you might be a threat to them in some way, or they think you might cause a noise if you move in next door. There's all these different actions, tiny little violences that people experience every single day of their lives.

(10:32):

We did have another, so many billions of examples, but there was an audit in the UK by some social workers a few years ago where they went around and knocked on supported living houses at about eight o'clock at night to see... It was called the bedtime audit and they found most people were in bed. In some of our research, previous research, we found people who put to bed at five o'clock with the radio on.

**Keith Casebonne** (10:55):

Oh my goodness.

**Jodi Beckstine** (10:55):

Wow.

**Sara Ryan** (10:57):

And this is fine. I mean, it's just baffling, isn't it? You're not allowed to drink after 6:00 PM. This is fine. Nobody else is subjected to these... Well, not nobody else, but most people aren't subjected to these restrictions.

**Jodi Beckstine** (11:12):

Goodness.

**Keith Casebonne** (11:13):

That's amazing. And the point, unfortunately in most cultures, segregation means scary. If someone is separated, someone is apart, someone is not there, something is not right. And so we need to be at least cautious, if not afraid. And so the continued... It's an interesting point that that continued sort of separation is kind of going hand in hand with these attitudes and this idea that something's not the same. And that's really incredible. I never thought of it that way, but it's a really interesting point.

**Sara Ryan** (11:53):

We had a report that was published a couple of years ago by Sheila Hollins about solitary confinement of people with learning disabilities, who were just in assessment treatment units, but they were being segregated and existing in solitary confinement. And in prison research, solitary confinement is the worst punishment possible. And yet, this study found that people with learning disabilities have been in solitary confinement for years without any crime. It's never condonable, but these people who hadn't committed a crime, they hadn't done anything, and yet it was fine to confine them on their own.

**Keith Casebonne** (12:28):

No.

**Sara Ryan** (12:29):

It's shocking.

**Jodi Beckstine** (12:31):

Yes. It's this out of sight, out of mind. You don't see it, you don't know about it attitude. I want to talk a little bit more about people in the systems behind all of this. Because it's not just individual attitudes, there's this whole structure that keeps these barriers and these things in place. Your book talks about the people and the systems that allow these harms to continue, sometimes on purpose, sometimes just out of ignorance. What or who are the main players and what are some examples of how this happens?

**Sara Ryan** (13:09):

It's a massive question, isn't it?

**Jodi Beckstine** (13:11):

[inaudible 00:13:11] it is.

**Keith Casebonne** (13:12):

Truly, yeah.

**Sara Ryan** (13:15):

I know. Well, I just... The main players are people in key roles, I suppose, who don't intervene, who allow it to keep happening. Because I mean, what we've even talked about in 10 minutes is human rights breaches left, right, and center, aren't they? And yet we know about this and nothing happens. So who are the key players? All sorts of... I mean, politicians, everybody in the collective, I suppose, plays their part, don't they? And that's the bit I have... In the book, I just introduced the collective and now I'm puzzling over, what is it about these people who refuse to see what's happening? And I was following Hannah Arendt's banality of evil sort of idea around, is it just thoughtlessness, that if you don't think you're capable of doing anything, but then is it easy to be thoughtless when you don't see the person in front of you as a person?

**Jodi Beckstine** (14:16):

Right.

**Sara Ryan** (14:17):

Is that the problem, that if you don't see the person as a human, then you don't have to think about what happens to them?

**Jodi Beckstine** (14:22):

True.

**Sara Ryan** (14:25):

And that's where I'm at at the moment, but I'm still puzzling it over. It's really difficult and it's really depressing.

**Jodi Beckstine** (14:31):

Definitely. It's hard to... You can't pinpoint it to one exact thing, one exact thing that you just fix and just flip the switch and fix the issue.

**Sara Ryan** (14:45):

Yeah.

**Keith Casebonne** (14:46):

Yeah, yeah. Systemic, it's through and through. So you mentioned case studies, including your own son's story, and historical examples like the Vipeholm Institute in Sweden. Can you share a story from your research that stays with you and what it tells you about the broader problem?

**Sara Ryan** (15:05):

Well, I mean, that Swedish example is a really good one because one of the things I saw worked through in the book is that when there is a scandal involving people with learning disabilities, because there occasionally is, and you could see them across the world that there's the odd scandal, the response to the scandal tends to improve things for everybody other than the people with learning disabilities. And the Vipeholm, if it is Vipeholm Institute was in the 1950s, a dental surgery was created in a home for children learning disabilities, and a set of children within that home were force fed... Well, not force fed because I bet they loved it at the time, but were given toffees to eat for nine years and the impact on their teeth was traced. And this led to tooth developments and improvements across the globe.

(15:58):

So much was learned from that experiment. And yet, even to this day, people with learning disabilities, certainly in the UK, are losing their teeth earlier and experiencing toothlessness, even though you think surely if there's a scandal involving people with learning disabilities, surely the improvements that come out of that scandal should improve the lives of that group, let alone anybody else, but it doesn't. It seems to improve everybody else's lives. And there's a lot of... Well, not a lot. There's quite a few examples of that. There's a terrible case in South Africa, 2015, where they shut a massive institution down. I don't know how you pronounce it either, Esidimeni. And they were told that this is going to have a terrible impact on the people who are being moved to unregulated homes across South Africa. The local authority was told this is going to cause harm, and yet they went ahead and did it and they know that 144 people died. They all had natural causes on their death certificate-

**Keith Casebonne** (17:05):

Of course.

**Sara Ryan** (17:06):

And some of them were moved shackled in open trucks. I mean-

**Keith Casebonne** (17:10):

Oh my God.

**Sara Ryan** (17:11):

Once you start looking into this stuff, it's just this sense of horror and bleakness. But this actually in the South African case, there is a prosecution that is going to happen to those officials who went ahead. And that is rare that somebody actually gets to be held accountable for this stuff.

**Jodi Beckstine** (17:29):

Right.

**Keith Casebonne** (17:29):

Wow. Wow.

**Jodi Beckstine** (17:30):

That's just heartbreaking.

**Keith Casebonne** (17:32):

Glad to hear it, but unfortunately, yeah, it should happen more often that they get held accountable. That's... wow.

**Jodi Beckstine** (17:40):

Well, I'm curious after all the research and personal experience that you've put into the book, what changes do you see are the most urgent at a policy level and at a personal level for people that may work in health or social care?

**Sara Ryan** (18:03):

Yes. There's all sorts of interventions that are produced through research findings. There's all sorts of swanky ideas. There's all sorts of new concepts that come up like person-centered planning. But I don't think any of this is needed. You just need to listen, and you need to be attentive, and you need to be open-hearted. I write in the book about Durkheim, a French sociologist who talked about the importance of the space around all of us. And if we don't respect that space that is around all of us, we are not a fair and humane society. And I sort of feel like we need that collective of people to wake up really. Wake up, see what's happening, and act on it. It's nothing fancy. Just wake up-

**Jodi Beckstine** (18:52):

Agree.

**Sara Ryan** (18:53):

And actually what I've been saying here, what I've been saying in this podcast, you're both really shocked by it. And yet in the UK, we had a scandal in 2011, some journalists went in undercover into an assessment unit where people with learning disabilities were living. They thought they were going to be there for weeks. One of them went into work as a support worker. He got the footage of the abuse within about two or three days because even the workers in the place didn't stop the abuse when somebody new came in.

**Jodi Beckstine** (19:22):

Wow.

**Sara Ryan** (19:22):

And there was a total furore about this case in the UK. There was sort of like [inaudible 00:19:30], everybody was so shocked to see visible evidence of people being treated like just so beyond, just unspeakably. It's a massive furore, and then every sort of few years since then, we've had a similar undercover documentary that's gone in, found exactly the same, and nobody even watches them anymore. There's no response. I went up to the BBC... I went up to a TV studio after one of these programs at about eight o'clock in the morning after it was filmed for a big breakfast meeting with the then health secretary, health minister, with a whole set of people, family carers. We were all there around the round table, but nobody had watched the program or commented on it. So we just had to have a sort of cross on and go home. So the horror, people get used to the horror too quickly.

**Jodi Beckstine** (20:21):

Yeah.

**Keith Casebonne** (20:22):

Yeah. And I guess that's that complacency. It's just one of the many factors that I guess continues to lead to these things continuing to happen. It just becomes commonplace and people shrug and go, "Yeah, again," and move on. That's somewhere it's got to stop.

**Jodi Beckstine** (20:40):

I watch a lot of documentaries and suggest them to friends and stuff. And I've had people say to me before, "Well, I don't want to watch that. It's depressing or it makes me feel bad." And it's like, that's the point. You should feel uncomfortable. You should feel bad. This should give you a reaction. Just dulling your reaction, I only want to see happy things that I enjoy and like is what's kind of led to a lot of these problems where people aren't looking outside themselves at what's really going on in the world.

**Keith Casebonne** (21:09):

Yeah, for sure. Well, we always end our interviews by asking our guests if there's a book, a film, a song, TV show, any sort of media that you would want to kind of mention, call out, recommend that either also shines a light on the issues that you've been talking about today, or just maybe just inspires you in general as far as your work, your advocacy.

**Sara Ryan** (21:41):

Oh my goodness. You put me on the spot here. Oh. I actually always chuckled about Something about Mary film.

**Keith Casebonne** (21:55):

Oh.

**Jodi Beckstine** (21:57):

Yeah.

**Sara Ryan** (21:58):

Because it was so outrageous. I mean, it was just so funny and yet it just captured the human and this sort of absurd storyline. But with, I can't... Well, Mary, I suppose, Mary and her brother, their relationship and their love for each other, and that sort of like... I love things that capture that, just the everyday love that people have for each other that is totally obliterated in this space. So things like that, I really, really love.

(22:28):

A lot of the media coverage or films tend to go down the stereotypical, cringe root. So there's not a lot. But I know I'm going to kick myself after this and think, oh, I love that, I should have said that. But yeah. And in terms of reading, I don't know. There's a book written by Simon Jarrett called Those They Called Idiots, which is a history of people with learning disabilities. And that goes back and he plots this root of what used to happen, and it's really lovely because he's sort of showing before the Industrial Revolution, or even two or three centuries ago, there was communities, and communities involved everybody. We hadn't started to really exclude people at that point. And you'd have judges coming in and letting somebody off for a crime because they didn't really know what they were doing or understand what they were doing, or it wasn't really a crime in some respects. It's just a lovely read of where we were and where we are now and how we lost people along the way, I suppose. We lost our way. I think we lost our way, and that's where we're at.

**Jodi Beckstine** (23:48):

Yeah. I think the key to what you're saying is the community. We've lost that bit in our world of big picture, where a giant community where it's easy to cut people off a little bit, as opposed to small, little villages or what have you.

**Sara Ryan** (24:04):

And by cutting them, we're cutting certain people off. And what we're doing is we're losing the contributions that people with learning disabilities make to our lives-

**Jodi Beckstine** (24:14):

Absolutely.

**Sara Ryan** (24:14):

Which a lot of people don't recognize those contributions as such. And certainly, obviously we've had an unspeakable loss in that respect, but I work with a lot of people with learning disabilities, I've got a lot of friends who've got learning disabilities. And to ignore what they bring to our lives in all sorts of different shapes and forms, it leaves our whole society impoverished. We're missing out and that's terrible and that needs to be addressed.

**Jodi Beckstine** (24:48):

Yes.

**Keith Casebonne** (24:51):

Well, I thought those were great answers.

**Jodi Beckstine** (24:54):

Yes.

**Keith Casebonne** (24:54):

Thanks for sharing that. And again, Professor Ryan, thank you so much for joining us. We really appreciate your time and all the work you're doing in this area. And yeah, it sounds like those big changes need to happen and it's good to talk to someone that's on the forefront of trying to see that those changes happen.

**Jodi Beckstine** (25:18):

Yeah. The education is important. Thank you so much for your time.

**Keith Casebonne** (25:26):

Stay tuned. This week's deep cut is coming up.

**Jodi Beckstine** (25:32):

Before we begin, a quick content note, When Barbara Met Alan takes the true story of two disabled activists who use bold, sometimes disruptive, direct action to challenge discrimination in the UK. The show includes moments of protest, police confrontation, nudity, and sexual themes, along with strong language. It doesn't pull punches because neither did the movement.

**Keith Casebonne** (25:55):

Today, we're talking about When Barbara Met Alan, the BBC drama that brings to life the story of Barbara Lisiki and Alan Holdsworth, two trailblazers who fought for disability rights and paved the way for the UK's Disability Discrimination Act or DDA. If you're listening from the US, you might recognize echoes of our own ADA passed five years earlier. Both were won by people who refused to take no for an answer, who took to the streets and who demanded change when the system stalled.

**Jodi Beckstine** (26:25):

Okay. So the film shows activists chaining themselves to buses, blocking traffic, demanding the right to just live and move and work freely. Do you think this kind of direct action is still needed today? And what can today's activists take from the Disabled People's Direct Action Network and their tactics?

**Keith Casebonne** (26:46):

Yeah. I mean, definitely reminded me of some of the same things that were happening around the 504, like sit-ins and things like that around that time. And I guess it's... I mean, the question is, do we still need this direct action? That's a very tough question because I think in some ways, yes, in some ways, no. I think it's a pretty nuanced answer, and I'm sure we'll get into it. But to some extent, I kind of feel like the basics for rights are kind of now set in law, and so maybe some of these types of more extreme physical and direct protests aren't as necessary. But then again, sometimes I think people forget and we get stagnant and maybe an out of the blue, good, old-fashioned protest might make some people go, "Oh, yeah, this is still something we have to deal with." So it's a tough question to answer, I think.

**Jodi Beckstine** (27:57):

Yeah. The scariest part for me is you have to put your body there-

**Keith Casebonne** (28:03):

Very true. Yeah, great point.

**Jodi Beckstine** (28:04):

And for disabled people, it's a really scary thought to put your already body that's got its issues, whatever they may be, in harm's way. I thought about the Capitol Crawl was part of that too. People kind of think about, oh, well, they crawled up the steps. It's so brave, that's so whatever, but that was dangerous for them. A lot of those people, that was really dangerous. But sometimes it takes those actions to get the public's attention. Because the normal things that you're doing, speaking to lawmakers, writing letters, making phone calls, the lawmakers usually kind of know what's going on, it's trying to get the general public behind you. And sometimes, that does take these big, bolder actions where finally the news is going to get involved and your story's going to get out there. So I think it depends on... We're a little bit luckier here. We'll talk about this as we get further into this with the ADA versus the DDA, but I think sometimes it does require it, unfortunately. And for all, not just the disability community, sometimes for all action to make changes, it requires-

**Keith Casebonne** (29:36):

Right. Yeah, no, yeah. Those are really good points. I totally agree. Another aspect of things being different today than they were then is we do have more outlets for legal advocacy and things like that. But there's also, social media, I think, is a huge difference for the good and bad of social media. That's a whole conversation in itself. But social media has certainly shown that it can be used as a way of mobilization, of sharing ideas and movements and uniting people.

(30:16):

I mean, the first thing that comes to mind when I think of a social media movement that was very, very successful was the #CripTheVote movement. And there's certainly others, but that's the first one that comes to my mind. And it was very successful. I mean, it still is an actively used hashtag today, even though it started quite some time ago. I forget how many years ago, but I mean, it was a while ago now. And it's still active, it's still talked about. So that's another... And that was all online. I don't believe there was ever any physical presence related to that movement, but you can't argue that it wasn't successful. So I think that's another outlet we have nowadays. I want to say it's physically safer. It might not be safer in other respects as far as social media goes in general. I don't mean these movements, I just mean social media in general. But certainly you're safer at your phone or computer than you are crawling up the Capitol steps. So it's another aspect of something that maybe is an alternative to what maybe we didn't have then.

**Jodi Beckstine** (31:29):

Yeah. And it's a way for the disabled community to take part in what's going on without having to physically be there. A lot of times, even when it has nothing to do with disability, there's so much intersectionality with a lot of things that are going on. So it's a way for the disabled community to participate with, again, not putting themselves in physical harm or just some people have heat intolerances and you're out, like with us in the Florida heat, it's just not feasible.

**Keith Casebonne** (32:01):

Truly. Truly.

**Jodi Beckstine** (32:01):

But by doing other things through this connection of social media is a good thing.

**Keith Casebonne** (32:08):

Yeah, totally agree, totally agree. Well, so When Barbara Met Alan doesn't just celebrate victories, it also shows burnout, setbacks, and how hard it is to sustain a movement. What stood out to you about how the film portrayed that personal cost of activism? And what do you think keeps people in the fight even when the progress is slow or even invisible?

**Jodi Beckstine** (32:32):

That's a great question. I like that it didn't just focus on the potential of wins for them. It was messy and exhausting. And they had burnout, they had personal conflict that happened between them, and times of just showing up for them felt like impossible. And there were times when he could show up and she couldn't. And their relationship had its ups and downs due to their activism. So to see all the messiness, it makes you wonder, and they did themselves, is what we're doing even making a difference. Is this even worth it?

(33:23):

And we talk about that being in Florida and being in the US, there's the public side, which are the protests like we were just talking about for fair housing, for voting, for education. But there's this private side where you're making phone calls, you're in these social media groups, you're writing emails. And what it feels like to hit an emotional wall when you're working on something and you don't see any change or it gets shut down, that's rough. And when you're fighting for your own life and your own dignity and your own independence, and it feels like it's sometimes just throwing your hands up and giving up is just not an option because it's your life that you're talking about. And so I liked that they really showed that side. It wasn't just about the protests and them going here and there and building this grassroot movement, it was really, we had those intimate moments in their home and seeing the reality of the toll it took on them.

**Keith Casebonne** (34:35):

Yeah. I mean, a really good portion of the film focuses on Barbara and Alan's relationship. And even though they want the same things, they would differ quite often on the path to take. And like you said, you could see how that affect... maybe they wouldn't have stayed together regardless of the protest and the other things, but it certainly seemed as if the work that they were doing for the movement affected their relationship enough that they couldn't stay together. And I don't want to blame it entirely on that because there's so many reasons why a relationship doesn't work out, but it certainly looked like a very large portion of why they didn't work out together as a couple. They still were together in the movement, they still were there, it's just they couldn't share a life and a house and so on together anymore.

(35:29):

There's moments when Alan starts to really withdraw and he... I think there's a line, I think Barbara says it to him, says that he started to want the fight more than the result. And so I think there's the aspect of identity also when it comes to this sort of thing, and I feel like for Alan especially, it was a lot of his identity to be that fighter. And so when there were times when it looked like Barbara might be saying, "Well, we have to sort of take a step back from the fight per se, the protests, maybe more specifically, because well, we're going to try to get these laws changed and now we need to not be so, whatever."

(36:14):

And whether you agree or not with that approach, she was thinking maybe we need to sort of take a more, I don't know, professional approach to him that was like, "Oh, so we just sit in our little spaces and we just..." And this isn't an exact quote, but something like, "We're just going to be the good, well behaved, disabled people instead of being out there and protesting." And so there's a lot of back and forth like that and they both want the same thing, but there's so many ways to do it that there's interpersonal dynamics of differences and it's a very challenging, stressful thing for all involved quite honestly.

**Jodi Beckstine** (36:51):

She challenged him several times like, "Are you doing this for yourself or are you doing this for the movement?" And I liked that moment, because sometimes it's a personal thing, so it's hard to take the personal aspect of it when you're dealing with a big community or a big idea. So I liked that dynamic of her trying to think of it as this big grassroots movement and him fighting for his life almost and that difference. So I think they did really well in explaining that, showing that.

**Keith Casebonne** (37:29):

Yeah, yeah, yeah, definitely I agree.

**Jodi Beckstine** (37:31):

So let's talk about the laws themselves. This is something that was very striking to me, the difference between the UK's DDA and the American's ADA. They both have promised civil right protections for disabled people, but each came out of a unique history. What similarities and differences did you see between the two movements and how did you think their grassroots activism shaped the laws that were finally passed?

**Keith Casebonne** (38:02):

Yeah. So I think grassroots movements are probably very important to both. I do think that there's probably a lot of similarities. I was actually... It's funny, and sometimes I think, okay, we're here in the US where sometimes laws are slow to happen and we're not always on the cutting edge compared to some of the world when it comes to certain things regarding civil rights and so on. But then when you look back at the dates of some of the civil rights legislations, including the ADA, I'm always surprised to see that, or I'm often surprised let me say that, that a lot of times the US has actually passed their laws first. And so in the case of the ADA, to me, 1990 doesn't seem like all that long ago. I mean, it just shows my age. I mean, honestly, God, it's like 30 something years ago now, but to me it was like yesterday, but still, it feels like that's just too recent. Some of this stuff had to be figured out way back, like '60s even or whatever, right? But yeah, 1990.

(39:12):

But then when I hear that nothing had even been passed yet in 1990, and again, I mean, well, it was 1994, I think, when they finally got somewhat usable legislation passed, I'm just always like, "Well, okay." So that's a difference right there in some respects, it's just the timing. I always feel like we're too slow in these things, but maybe we're not. Sometimes I think this makes me feel a little better about the speed at which some of these things happen here. I think speed might be a very relative term, but just compared to other places, maybe we're not as bad as I sometimes think, and I need to remember that.

**Jodi Beckstine** (39:53):

Well, even the conversation with Professor Ryan that we had in the first segment, she talked about things that were still happening that are not... They are laws against that here in the US. And I remember us being shocked to hear her say those things. So to me, the ADA seems... We feel like it's not covering everything, there's still so much work that needs to be done on it, there's still so many laws that aren't enforced, but the DDA was just really kind of, for lack of a better term, it seemed almost placating like, "Yes, we agree you need these civil rights. Yes, we agree we're not doing that, but we're just not going to do a whole bunch about it." That's in the context of Barbara and Alan. I haven't really reviewed it in the present day, but-

**Keith Casebonne** (40:45):

We're not historians of British legislation. We don't know the whole... Yeah, right.

**Jodi Beckstine** (40:49):

So I felt like both need a lot of work in general. There's too many loopholes and too many things that aren't enforced and too many... That's why we have the job that we have is to do what we do. But yeah, I was really surprised at the stark difference. They're both starting the same, the grassroots, the need, but just how it kind of ended up, the laws ended up was shocking kind of to me.

**Keith Casebonne** (41:21):

Yeah, yeah. And so what you're kind of saying here is that the ADA, when it came out in 1990, I mean, it was built to be strictly like, "These are the things that you cannot do anymore. You have to change this." And they're actionable. You can file a suit on behalf of the ADA and say that. Whereas that, at least, I think it's evolved, but at least in '94, the DDA, when it first came out, they mentioned very plainly in the film that it's not a great law. Like you said, the purpose was more that it identified that people's rights were being violated, that people with disabilities' rights were being violated. It didn't really do much about how to fix it, but it was a start and at least it got that put into their laws that it is considered discrimination.

(42:13):

So it gets built on and that's great, but yeah, that's definitely a very different path than our law comes out and you can file a suit if you have to right off the bat with it. And I don't think they had those grounds there. I don't know the status of it now. I don't know... I'm sure it's been built upon and things have gotten to some degree better, but I don't honestly know. It's a very different path that it's taking. And really, even though you can say it technically passed in '94, it might not have been all that usable or actionable until years later.

**Jodi Beckstine** (42:50):

Yeah. I think, again, the public got involved and kind of understood what was going on based on them protesting. And so I think for the government, this is my opinion, it was kind of like, "Okay, well, we'll pass this and we'll agree that you need these things, just get out of the street. Stop stopping traffic, we'll do what it takes to just make that stop." And that's where I come up with it being placating because I feel like it was just really like, yeah, just get on the road please so that we can move on with our lives. And unfortunately, it's not enough. And things are evolving, society's evolving. It's really never enough until everyone has accessibility and equality. So it's always changing, it's always building, it's always growing.

**Keith Casebonne** (43:42):

Yeah. And that's going to always be a moving target and something that changes all the time. Well, as we're saying, the film makes it quite clear that passing a law is not the finish line. In both countries, there are certainly still barriers, physical, legal, attitudinal, and so on. So what do you think needs to happen for the promise of equality to become a reality? Where are we falling short? And what can listeners even do now?

**Jodi Beckstine** (44:08):

Yeah. Passing the laws, again, like you were saying is just the starting line. The ADA and the DDA set big expectations, but barriers still exist. There's still buildings that are inaccessible, there's still polling sites that are inaccessible. The attitude is that making things accessible is an afterthought or look how great this person is for making this building accessible. It's like cheering on like, look how great they are, they put a roof on the building. To me, it just needs to be part of what's happening. It's nothing special, it's nothing extra, it's just the law. If it's accessible for one person, it can be accessible for everybody. It's not a one size fits all. And even in Florida, in the US, we hear about these things still, even though we have these stronger laws.

**Keith Casebonne** (45:05):

Of course.

**Jodi Beckstine** (45:06):

I find it many times going about my day, things that are inaccessible as a mobility scooter user. And it's what do you do? Do you stay silent? Do you make a big ruckus? It depends. Sometimes I will, sometimes I need to get done what I need to get done. So I think the biggest thing is we need enforcement of the laws. I think just having this stuff on paper is not enough. Then I think we need that shift in attitude, where people thinking that accessibility is this extra thing. You have a parking pass, you get to be upfront, you get to be first, you get this extra thing, I have to park back here. It's that type of attitude that bothers me the most.

(46:08):

And everyone can do something about it. Just because you may not be part of the disabled community, you could see what's accessible, you could see when someone's having an issue with accessibility. If you're a poll worker and you're setting up a polling place, you know if there's nothing there for accessibility, you can speak up, you can do something. So I just think getting the public kind of involved, even if they're not part of the disabled community. So again, enforcement and just speaking up and doing something about it.

**Keith Casebonne** (46:46):

Yeah, yeah, totally agree. And the other thing too is that even though these laws were in place, our world changes and sometimes a law written X number of years ago is going to need to either be amended or adapted or maybe new guidelines set forth to keep it current. And I think a good example, and of course I can speak more to the ADA, but I would imagine it's very similar in other parts of the world, in 1990 when the ADA was passed, well, we didn't have the public facing internet. The internet was around, but as far as just us average Joes go, there was no internet in 1990. And so there weren't websites, there weren't things like that that had accessibility concerns.

(47:31):

And you can totally argue, of course, that, and I think rightfully so, you can argue that, okay, well, a business's public facing website is another aspect that should be considered, or government, or any private or public entity, their website should be accessible for people with disabilities. And that still is a huge challenge. So people have built their businesses or adapted their businesses to make sure that the restrooms are accessible, that there are ramps getting in, not even always 100% the case, but much more broadly than maybe the... But yet some people's websites are still very much inaccessible or other things like that. So the barriers have just shifted a little bit. They're still there, they're just, you're finding them maybe in different ways than you generally did in 1990.

(48:21):

And so we need to adapt and think of it. And that's still something where either laws need to be amended or the Department of Justice kind of puts out guidelines and it's kind of gone back and forth in recent years, but they sort of can set the tone and say, "Yes, we consider that a website is part of that public or private facing storefront," if you will. So yeah, there's always things that are changing, there's always things that need to be looked at. And I guess the fight's never going to end. There's always going to be something. There's always going to be a reason to protest, whether that's in person, online, through writing, who knows. But I think, even when the laws are in place, our world changes, we all have to adapt, and sometimes those laws need to adapt.

**Jodi Beckstine** (49:13):

Yep. Well, just now we have AI coming in.

**Keith Casebonne** (49:17):

That's another one, yeah.

**Jodi Beckstine** (49:19):

That's going to be a whole ball of wax. And then when we have, I'm sure there'll be barriers when we have flying cars. So we have to find out the-

**Keith Casebonne** (49:27):

That's right, flying cars are not accessible. I'm saying it now.

**Jodi Beckstine** (49:32):

Let's get ahead of it.

**Keith Casebonne** (49:35):

That's right, that's right, that's right. Awesome.

**Jodi Beckstine** (49:37):

All right. So well, today we dug into history of the fight and the personal side of disability rights activism on both sides of the Atlantic.

**Keith Casebonne** (49:46):

Yes. When Barbara Met Alan is a powerful reminder that change doesn't happen by accident. It takes persistence, creativity, and sometimes raising a little hell.

**Jodi Beckstine** (49:56):

Whether you're new to the movement or you've been in it for years, these stories are for all of us. The work isn't finished, but every step forward matters.

**Keith Casebonne** (50:04):

Yes, it does. Thanks for joining us for this deep cut. Keep speaking up, keep learning, and keep pushing because that's how progress happens.

**Jodi Beckstine** (50:14):

That's it for this episode of Disability Deep Dive. A huge thank you to Professor Sara Ryan for sharing her research, her passion, and her commitment to making these issues visible.

**Keith Casebonne** (50:23):

Yeah, indeed. Dr. Ryan's work reminds us that preventable deaths in individuals with intellectual disabilities aren't just a statistic, they're a call to action. Each listener has a role to play in challenging the systems that allow this harm to go on.

**Jodi Beckstine** (50:37):

If this conversation moved you, make sure to subscribe, leave a review, and share it with someone who needs to hear it.

**Keith Casebonne** (50:43):

And you can find Dr. Ryan's book, Critical Health and Learning Disabilities: An Exploration of Erasure and Social Murder, wherever books are sold. And as always, links and resources are in the show notes.

**Jodi Beckstine** (50:54):

Thanks for listening. Keep asking the tough questions and keep pushing for change. We'll see you next time on Disability Deep Dive.

(51:01):

Disability Deep Dive is a podcast that is brought to you by Disability Rights Florida, where real conversations about life, culture, and ideas meet the lived disability experience. Follow us on YouTube, Spotify, and wherever you get your podcasts. You can also find us at disabilityrightsflorida.org/podcast.