

## April 2022 APS TARC Podcast Transcript

### Recognize, Report, Respond (R3) - Co-Designing a Technology-Based System With and For People with Intellectual and Developmental Disabilities

#### [00:00:00] Introduction

[00:00:00] **Krista Brown:** Welcome to the Adult Protective Services, Technical Assistance Resource Center, APS TARC podcast. The second in a series of podcasts planned for this year. We come to you with the goal of sharing promising practices and innovations from various APS programs who have received Administration for Community Living, discretionary grants.

We hope to highlight what is achievable with fresh ideas and new partnerships to help you envision what may be replicated in your program. In this podcast, Jennifer Spoeri, APS TARC subject matter expert Mariah Freark Deputy General Counsel for the Commonwealth of Massachusetts Disabled Persons Protection Commission.

John Mullaly and Brian Kelly, both with MASS Advocates, Massachusetts Advocates, Standing Strong, discuss the person-centered collaborative co-design co-development co [00:01:00] implementation of an enhanced technology-based education and reporting system called Recognize Report and Respond R3 for use by people with intellectual and developmental disabilities.

Before we go to our interview a quick disclaimer, the Adult Protective Services, Technical Assistance Resource Center is a project of the U.S. Administration for Community Living Administration on Aging Department of Health and Human Services and administered by WRMA incorporated, contractors, findings, conclusions, and points of view do not necessarily represent the official policy of the federal government.

For those that may be new to adult protective services and not familiar with the APS TARC our mission is to enhance the effectiveness of state APS programs by supporting federal state and local partners. Use of data and analytics. Applying research and evaluation to [00:02:00] practice and encouraging the use of innovative practices and strategies.

Now let's join Jennifer Spoeri, Mariah Freark, John Mullaly and Brian Kelly in conversation.

#### [00:02:13] Interview

[00:02:13] **Jennifer Spoeri:** Hello, I'm Jennifer Spoeri I'm going to introduce Mariah Freark

Mariah is Deputy General Counsel for the Commonwealth of Massachusetts Disabled Persons Protection Commission. Also known as DPPC. DPPC's Administration for Community Living, Adult Protective Services Enhancement Grant is utilizing technology to create a common data reporting system that partners.

DPPC with stakeholders to create an enhanced technology-based abuse, education and reporting system called Recognize Report Respond or R three for use by people with intellectual and

developmental disabilities. Mariah, please tell our listeners about your path to APS and the Disabled Persons Protection Commission.

[00:02:59] **Mariah Freark:** Hi, [00:03:00] Jennifer.

Thanks for having us on today. Let's see here. I went to law school at the Northeastern University School of Law in Boston here in Massachusetts. And after I graduated in 2010, my first job was. Working as the attorney investigator at the Cambridge Human Rights Commission, which is a city of Cambridge department responsible for enforcing the city's anti-discrimination ordinances.

And our office was right next to the Cambridge Commission for Persons with Disabilities. We worked very closely with them as well as other city departments, but I ended up doing a lot of disability related anti-discrimination law, a lot of housing, reasonable accommodations and that was really how I kind of stumbled into the world of disability rights.

And I was looking to swim in a bigger pond after my first, you know, probably five or six years as an attorney. And so ended up here at DPPC in 2015.

[00:03:55] **Jennifer Spoeri:** Wow. All of that experience probably serves DPPC very well, [00:04:00] considering all the different legal aspects that you encounter. So now I'd like to introduce Brian Kelly.

Brian works for MASS advocates and is. Yeah, is on the DPPC advisory board as well. So Brian, tell us what MASS Advocates stands for the acronym.

[00:04:21] **Brian Kelly:** Well, it stands as self-advocacy. People with disabilities that have our self-advocates.

[00:04:28] **Jennifer Spoeri:** Massachusetts Advocates for Standing Strong, standing strong, standing strong.

Okay, great. And you're also on the DPPC advisory board, like I said, so you do wear many hats. You're absolutely right. So, tell us, how did you get involved in self advocacy?

[00:04:44] **Brian Kelly:** Well, I started in 1993 when I moved to Milford, when the guy goes to, oh, you should come to these meetings, we need somebody like you.

Who's good at speaking up and. Yeah. And I started going to the self-advocacy [00:05:00] meetings in 1993.

[00:05:04] **Jennifer Spoeri:** Yeah. And now you lead them, correct?

[00:05:06] **Brian Kelly:** Pretty much. And then I was on the board directors for alternatives,

[00:05:12] **Jennifer Spoeri:** For alternatives.

[00:05:14] **Brian Kelly:** Yep. Which is now Open Sky.

[00:05:17] **Jennifer Spoeri:** Wow.

[00:05:17] **Mariah Freark:** For service providing agency. Yeah.

[00:05:21] **Jennifer Spoeri:** You do wear many hats. Thanks, Brian. So, anything else you want to add about your path to self-advocacy?

[00:05:26] **Brian Kelly:** That's good for you have to speaking up, you know, speaking up is what you want, you know?

[00:05:31] **Jennifer Spoeri:** Yeah. Only, you know what you need best, right?

[00:05:34] **Brian Kelly:** Yep. They can't read minds.

[00:05:37] **Jennifer Spoeri:** No. No.

I'd like to introduce John Mullaly. He works for MASS Advocates and MASS stands for Massachusetts Advocates Standing Strong. Right, John?

[00:05:49] **John Mullaly:** Right.

[00:05:51] **Jennifer Spoeri:** So please tell our listeners, how did you get involved in self-advocacy.

[00:05:57] **John Mullaly:** I got [00:06:00] involved in self advocacy in 1985. I got involved by being. The teenage ambassador for, for Rhode Island Easter Seals, I had to go into. Channel 12 Eyewitness news, make an appearance on the news and come back the following day [00:07:00] and. Uh, get people to donate the money to what is, what is a good cause. And i. And I really feel still is a good cause [inaudible]. Help me throughout my life.

[00:07:56] **Jennifer Spoeri:** Maybe you're the reason that that Massachusetts has such a [00:08:00] strong system for people with disabilities. I'd like to go that far.

[00:08:09] **John Mullaly:** Thank you for that.

[00:08:12] **Jennifer Spoeri:** And you've been an advocate for 37 years. That's nothing to sneeze at.

So, Mariah can you tell us about each of the partners involved in this innovative grant?

[00:08:25] **Mariah Freark:** Sure. DPPC was the, the grant recipient from the Administration for Community Living, but we knew, you know, even before we submitted our application, we can't do this on our own.

So, it was critical to involve. First of all, MASS Advocate, Standing Strong, we knew again, right from the beginning that we want the voices of self-advocates. Not just to be included, but to be central to the app that we're building. We didn't want to, you know, build something that we think would work without input from the, the end users of the people who would, who would be using it.

So we're working with MASS Advocate Standing Strong. We have a computer scientist, Dr. Krishna Venkatasubramanian who's down at the University of Rhode Island. And we have. Social

Psychologist Dr. Jeanine Skorinko, she's over at the Worcester Polytechnic Institute. And then we're also working with our state's department of developmental disabilities.

[00:09:20] **Mariah Freark:** So that's kind of the core group of folks working on this project.

[00:09:24] **Jennifer Spoeri:** Wow. A social psychologist and a computer scientist, all in one room. Mm-hmm along with DPPC and MASS Advocates. That's in that's incredible crew. So. I'm always curious about the vision behind these grants. And I understand there's a lot of older curriculum that's been built on how many partners have been a part of it.

[00:09:44] **Mariah Freark:** A lot, you know, same sort of same sort of critical stakeholders. Nancy, Alterio, the executive director for the DPPC. Got this project going, oh gosh. Well, before my time, 15 or maybe 20 years ago called the Awareness and Action Project, and this was a [00:10:00] curriculum. We got a grant from, I want to say it was the Office for Victims of Crime to develop a curriculum with, and for people with intellectual and developmental disabilities to help them recognize report and respond to abuse.

So, this is a curriculum that is. Team taught. There's an instructor with a disability and an instructor without a disability, and it's taught directly to people with disabilities. So, Brian is one of the awareness and action instructors, which is why he's such a great part of our project because

[00:10:29] **Brian Kelly:** Right.

[00:10:30] **Mariah Freark:** What we wanted to do was take this in-person training and, and the idea and the curriculum. That it had and try to turn that into an app just because we don't, we can't possibly replace the in-person experience, but that's, it's really good information. Not everybody knows what abuse is or you know, what you're supposed to do if you think you're being abused or somebody, you know, is being abused.

So, the awareness in action could curriculum is, was the foundation for [00:11:00] the R three app that we created. So, in the beginning, we thought we were going to be able to develop an app that would cover all of those three Rs. But you know, we discovered we had ourselves in iceberg. So, our first app is just focused on the recognize piece.

And so, it's basically an abuse, education, and prevention tool. For people to go through and learn about the different types of abuse. And then we do have a feature built into the app where you can contact the disabled person's protection commission or a trusted person. But we are looking at building out a separate reporting app to try to enhance the ability of people to report.

So that they don't have to make a phone call or don't have to go through like a lengthy, you know, online form that they would fill out. We're still sort of brainstorming what that looks like.

And then for the respond piece, we're in the process of using our COVID federal fund to build a self-care app, to help people who, you know, if, if they've been abused or if somebody that they know has been abused, you know, just to kind of.

[00:12:02] **Mariah Freark:** Work through that and take care of themselves and heal a little bit more. So we're, we're looking at this now to be kind of a complimentary suite of the three apps that, you know, ultimately will be able to interact together, but also will be able to stand alone.

[00:12:21] **Jennifer Spoeri:** Great. And the trusted contact component in the app is intriguing to me because other industries I'm thinking of financial exploitation with financial institutions, they use a trusted contact component.

So how does the trusted contact component work in this app? Is it,

[00:12:37] **Mariah Freark:** It's actually something that came out of the awareness in action training. Right. Brian, you guys talk about a, a trusted person.

[00:12:44] **Brian Kelly:** Yeah.

[00:12:45] **Mariah Freark:** So, you know, when they're, when they're doing the training, they say, if you, you know, who, if, if you're concerned about something or if you're, you know, worried about something, who do you talk to?

And so, it's the same sort of put into the app so that You know, the user, when they're [00:13:00] beginning to use the app can put in, oh, you know, I want my friend Donna to be my trusted contact and, and so preload her name and, you know, contact information. And then there's a button in the app that just says call trusted contact.

So when you press that button, it automatically brings up that person's phone.

[00:13:19] **Jennifer Spoeri:** That's an excellent feature. That's really great. So, think speaking of that, Brian other than the trusted contact app component, how, what other features of this app do you think would really benefit persons with disabilities?

[00:13:33] **Brian Kelly:** Like just said, somebody just pressed that DPPC and get her enhance from somebody. They press the button and they feel they're being hurt.

[00:13:45] **Mariah Freark:** Yeah. Yeah. They can call DPPC directly from the app.

[00:13:49] **Jennifer Spoeri:** Great. And we had spoken earlier, Brian, and you had said that it's 24, 7

[00:13:54] **Brian Kelly:** Yep. Seven days a week, 365 days a year.

[00:13:58] **Jennifer Spoeri:** Wow.

And, and that way, like the advocate meetings you lead, if you need something right now, you don't have to wait for that advocate. meeting.

[00:14:07] **Brian Kelly:** Right.

[00:14:09] **Jennifer Spoeri:** Great. Now other features for it I know you, you have a visual impairment and you had mentioned before about the large print

[00:14:16] **Brian Kelly:** And a speaking thing helps too.

[00:14:19] **Jennifer Spoeri:** Oh, wow. Okay. Tell me more about that.

[00:14:23] **Brian Kelly:** I don't know about on the app, on my iPad. I have a reader screen reader.

[00:14:28] **Mariah Freark:** Yeah, and we did. Yeah, we did build the app to be compatible with those kinds of screen readers so that the text is read for people who don't read.

[00:14:37] **Jennifer Spoeri:** Gotcha. That's pretty incredible and mentioned there's videos and games and things like that as a part of the app.

When who doesn't have a phone these days. I mean, there are certain people, but I'm sure it's really great to access DPPC immediately and be able to reach out to your trusted contact.

John what do you think this will bring to persons with [00:15:00] disabilities?

[00:15:03] **John Mullaly:** I think it will bring them more independence and freedom and more comfort.

[00:15:29] **Jennifer Spoeri:** You're speaking about the self-care part of the app, correct?

[00:15:33] **John Mullaly:** Right.

[00:15:34] **Jennifer Spoeri:** Gotcha. Yeah. That freedom and comfort are two very important things in my world. I'm thinking a lot of our worlds, right.

[00:15:44] **John Mullaly:** Right.

[00:15:46] **Jennifer Spoeri:** So I'd like to back up a little bit, just because I know COVID affected a lot of things in our world, but how did the kickoff. To getting this app off the ground or the organization of the project. How did that begin?

[00:15:58] **Mariah Freark:** It was a [00:16:00] relatively easy kickoff just because we have really solid working relationships with all of the stakeholders already.

So, you know, we, weren't starting from scratch and introducing ourselves and saying, you know, hi, we're DPPC and this is what we do. We were reaching out, out to people who are already really integral partners in our day-to-day work and saying, Hey, we want to do a little bit extra. And so, you know, we had kind of lined up our ducks, we got the money and we just hit the ground running.

And we started out by having in-person meetings.

And I know, I know we're going to get to that in a minute, but everybody was really enthusiastic and really excited from the get go. So, our, it wasn't, it, it wasn't really a kick. It was like, you know, a nudge like it was, we were, we were off and, and ready to go.

[00:16:42] **Jennifer Spoeri:** That goes to show you how important having partners and collaborators in the community are for, for us. So, yeah, let's get to the technology component, because Brian, I

wanted to ask you about that. How did COVID affect the project? Cause I know you were key in kick starting this and then COVID hit,

[00:16:59] **Brian Kelly:** Well, [00:17:00] we didn't get to see each other and real, but that got helped me learn zoom, you know,

[00:17:07] **Jennifer Spoeri:** We've all learned zoom

[00:17:09] **Mariah Freark:** Yes.

[00:17:09] **Jennifer Spoeri:** A lot of zooming. So yeah. And you had a lot of projects planned, you still were able to get these done via zoom.

[00:17:16] **Brian Kelly:** Oh yeah.

[00:17:18] **Jennifer Spoeri:** Wow.

So how did COVID affect your project? How did things have to change for you?

[00:17:25] **John Mullaly:** I have to agree with Brian, because in the start we got go out and see more team members. And. What they, what they got to do and how the [00:18:00] shaping, um, uh, that part of the app.

[00:18:15] **Jennifer Spoeri:** Yeah, it's different working face to face. Then on a screen,

[00:18:23] **John Mullaly:** Right

[00:18:24] **Mariah Freark:** It is. Yeah. And what, what John was talking about as far as shaping the app, we, um, we had planned to initially do, uh, a big month-long pilot test. When we had an app, all done and built, we were going to, um, you know, put a bunch of people in a room together and give them all and train everybody on how to use the app and then send them home and have them, you know, use these tablets and use the app for 30 days. And obviously we're not doing that.

So, our, our team did a phenomenal job. Switching it up and trying to figure out how to do that. Virtually Krishna and his team of students found an emulator so that they could make the emulator talk to zoom so that people could use the app through zoom.

Our, our computer scientist is really big on what he calls co-design, which is so it's, it's less like I'm going to build this thing and then see how you feel about it and more why don't we build this thing together.

I think it took a lot of like wizardry to make that happen, but it did. So, I'm, I'm really proud of how we were able to adapt. But, you know, like Brian said it was, it was hard not seeing each other in person both at our regular meetings and doing the pilot tests.

[00:19:35] **Jennifer Spoeri:** Yeah. Wizardry or a computer scientist on your team. That sounds pretty fascinating

[00:19:39] **Mariah Freark:** I mean, they're the same thing as far as I'm concerned, like [00:20:00]

[00:19:40] **Jennifer Spoeri:** Seriously,

[00:19:46] **Mariah Freark:** How is that? Not a wizard. I don't understand all.

[00:19:47] **Jennifer Spoeri:** All magic. So, I guess my next question is for Mariah, was this grant extended or if not, is it still funded? Where, where are you with things?

[00:19:59] **Mariah Freark:** We are wrapping up our no cost extension.

We were really grateful to ACL, but, you know, they acknowledged, I, I mean, as soon as the pandemic kicked in Elizabeth, Petruy, our contact was like, if you guys need more time, let us know. So that was really helpful, you know, we wanted, we wanted to do our best. And so, we didn't start thinking of a no cost extension right away, but it was nice to know that we had that as a backup in case we needed it.

And because the virtual pilots. Took so much more time. We did end up requesting and receiving that no cost extension. So, we are looking to wrap up our project on August 31st. We have a pretty final version of our app. We're hoping to present that at the NAPSA conference this year. And then we're also looking at [00:21:00] distributing this app more widely and making it open source so that it can be more generalizable so that, you know, people aren't, people can put in their own APS agency rather than having.

The call APS button called DPPC. So, this definitely is something, you know, from the beginning that we've envisioned sharing with other states, even the abuse education curriculum is not tailored to the Massachusetts abuse laws. It covers for example, financial abuse, which DPPC doesn't have jurisdiction over.

So, the, the app was designed sort of. You know, from the beginning to be something that could be used by a variety of people in a variety of places.

[00:21:25] **Jennifer Spoeri:** Yeah. That would be, I I'm sure that would be a well-attended session because the, if it was replicable across the country to other states, what a, what a great innovation you've just given to. your counterparts.

[00:21:38] **Mariah Freark:** Yeah. We're really excited to share it.

[00:21:41] **Jennifer Spoeri:** So, Brian, do you have any [00:22:00] final comments before I close wonder wonderful. Having you.

[00:21:46] **Brian Kelly:** I wasn't involved with the videos, but I was involved with the words in the curriculum. You know, the Awareness in Action.

[00:21:55] **Jennifer Spoeri:** Yeah. The Awareness in Action. Well, that's the foundation for this.

So, you've been involved since ground floor.



Well, so in closing, this project is truly groundbreaking and without the input of persons with disabilities like Brian and John, with over 66 combined years of self-advocacy experience, I don't think this would've been possible. The app has been designed with, and for people with disabilities,

What is it you all say nothing about us without us. I love that. I'm sure our listeners gain some good information, and we'll explore projects like this in the future. So, thank you again to Mariah, John and Brian.

### **[00:22:32] Closing**

[00:22:32] **Krista Brown:** Thank you very much for listening to give us feedback on this podcast or any other APS TARC product, please visit our podcast page [00:23:00] at [apstarc.acl.gov/podcast](https://apstarc.acl.gov/podcast). Take our brief survey or email us [apstarc-ta@acl.hhs.gov](mailto:apstarc-ta@acl.hhs.gov).