Introduction

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Kirsten: You're listening to the NCDPS Safety Scoop, a podcast that dives into the stories of the people, programs and resources within the North Carolina Department of Public Safety. Each episode, we'll give you the scoop from department personnel on how NCDPS enhances the safety of the people of North Carolina.

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Season 2 Episode 7

Kirsten: Prepare, prevent, protect: the three main components of the Department of Public safety's mission. In this episode of Safety Scoop, we focus on the protect and prepare components by discussing an up-and-coming training initiative not only happening within the department but all around the world. NCDPS provides exceptional public safety to members of our communities and visitors of our state no matter who they are. With this guiding principle, the Helping Enhance Autism Response Training, or HEART, program came to fruition in 2020. This training program aims to equip law enforcement officers and first responders with the resources and knowledge they need to approach situations where an individual with autism spectrum disorder is involved. The goal of our HEART program is to further safe contacts among law enforcement, first responders and individuals with autism.

Our two guests today are Chief Deputy Secretary of Administration Cassandra Skinner Hoekstra and national autism awareness expert and author Dennis Debbault. CDS Hoekstra, a founding member of DPS's HEART program, has a nonverbal son on the spectrum. She's first up as we take a look at what kicked off the HEART program and how it has impacted North Carolina communities. Well, excited to talk to you about HEART and this initiative, run through DPS. So, thank you for taking the time to talk with me.

CDS Cassandra Hoekstra: I am excited about it, too. Thank you for asking.

Kirsten: As a founding member of the HEART team, can you take us through the behind-the-scenes process that led to the establishment of this training initiative?

CDS Hoekstra: Absolutely. So, this began with Secretary Hooks. He had attended some training, FBI training I believe. The training was designed to help FBI sworn officers recognize signs of autism and learn strategies for safely interacting with individuals on the spectrum, and he came to me knowing that I have a son who has autism and asked me if I would sort of spearhead this initiative to provide some training. He wanted to do something related to autism and safety, and so he put me in touch with the trainer, and that's how it all began.

Kirsten: What have you learned during these training sessions?

CDS Hoekstra: I think what has been–has really hit home for me is how broad the spectrum is. You know, I have my own sort of narrow lens of autism with my son and–and those that live with him who are also on the spectrum. They're all very close in terms of their dependency and their functionalities, so to speak, but as part of this training you see where you have very high functioning individuals, those who are more independent, those who are driving, those are able to communicate for themselves, whereas my son, he would–he would require somebody else to communicate on his behalf. And just that law enforcement, any first responder has to be very alert to that and adaptable because there's no one size fits all for this approach.

Kirsten: And in your opinion, what are the most important takeaways that you've seen in this training that Dennis puts on?

CDS Hoekstra: Just being aware, and again, being flexible and adaptable because there—it is so broad. Being patient. You would want to modify how you–how you approach somebody on the spectrum. You know, like our conversation, for instance, and–and you know, you ask me a question. I respond immediately. Whereas with somebody on the spectrum, you may have to wait quite some time. It might be a full minute before they're able to process and respond to that question, and so just really being patient.

Kirsten: Well, we have had HEART sessions happening at least once a year since 2020.

CDS Hoekstra: That's right.

Kirsten: And so, who should attend trainings like this?

CDS Hoekstra: Anybody who has any role in responding to an emergency can benefit from these trainings. Of course, we have law enforcement, fire, EMS, telecommunicators. But anyone who has a role in potentially responding to an emergency situation where someone could be involved that is on the autism spectrum.

Kirsten: And as you have attended many of these sessions, what kind of feedback have you heard from past participants?

CDS Hoekstra: We've gotten very good feedback about the training. People are really excited about it. They're excited to hear that it's coming to their area. A lot of the participants have somebody in their family, somebody that they know who has a child with autism or an adult family member with autism. And so, they are so very grateful that we are putting this training on.

Kirsten: And it is one of DPS's kind of core initiatives.

CDS Hoekstra: It is, and I'm really excited about that. I mean, it really has become something that the public can look to DPS to–to provide.

Kirsten: As the parent of a child who is on the autism spectrum, what steps need to be taken to protect individuals who are nonverbal or find social settings challenging, um, you know, people who are on the autism spectrum or just people who may have other social anxieties or disabilities or anything like that?

CDS Hoekstra: Sure. I think the most important thing for parents such as myself who have children on the spectrum who are nonverbal–my son, for instance, is completely nonverbal and is very challenged in communicating with others, usually would require me or someone else in his presence to help him communicate. And so, I think it's very important for me and his caregivers to provide as much information or make as much information available… So, for instance, I have a decal on the back of my car that says, "occupant with autism: may not respond to verbal commands, may not talk, may not comprehend verbal commands, may not respond to their name." Those kinds of things would alert law enforcement, heaven forbid something happened, and I am not able to speak for my son or a caregiver is not able to do that.

I think the Autism Society has made similar decals. I think there are things you can include that the person can carry with them to identify himself or herself as someone who might need some additional support in terms of interacting and communicating with others. So, there are some tools out there that we can utilize as parents, and the department, for instance, has created a decal that we've been providing to parents.

Kirsten: I know it's hard not being a member of law enforcement to speak about what should law enforcement do.

CDS Hoekstra: I just think the training that law enforcement are open to participating in the training. And–and we have seen that a lot of members of law enforcement agencies are asking for, want to participate. I think they recognize. either because of their own family situation or a friend or somebody they know who has autism, I think they recognize that the chances, the likelihood of them interacting with someone on the spectrum is very high given the–the numbers. I think it should be a part of their annual training, in my own opinion, and–and there have been some–we've had some conversations about how we might do that in North Carolina, make that part of the in-service training for law enforcement. But other first responders as well to include these types of interactions in their Basic Law Enforcement Training.

Kirsten: I mean, in the current environment, there's–there are so many different types of people within communities. There's not really one specific way to respond to all situations, you know, whether or not someone is on the spectrum or not. So, I think that's a really good point that you bring up.

CDS Hoekstra: That is very true, and you know, I–I know of, I have friends who have family members who have dementia or Alzheimer's or similar types of cognitive impairments, and I think that this type of training gives law enforcement and

other first responders additional tools in their tool belt, so to speak, things that they can be on the lookout for and ways to safely engage and interact.

Kirsten: Though HEART is a training mainly geared towards law enforcement and first responders, are there any resources HEART can provide to parents or other caregivers that you haven't already spoken about?

CDS Hoekstra: One of the things that we're looking at doing is having open house events with some of our law enforcement officers here at DPS, our law enforcement agencies And also encourage local law enforcement agencies to have open house events where parents–caregivers–can bring their loved one who has autism into that environment to meet those first responders, to become familiar with the uniforms that they wear and just that environment, to sort of acclimate them to that and make them more comfortable with those, with interacting with somebody who presents in that way. And so, I'm really excited about that. I–I expect we will begin doing that hopefully this year.

I've talked with our trainer about this as well, and there been other conversations with other stakeholders about some other means by which we can alert first responders to the fact that there's somebody in the area that may have a cognitive impairment or autism in particular, something that, you know, that even a telecommunicator when they take a call to a particular address, perhaps knowing that there may be somebody in that area or somebody at that address that has autism and would need some additional supports in terms of keeping themselves safe.

Kirsten: Final notes that you want to talk about the training or how it's put on?

CDS Hoekstra: I would just say I am so honored to have this opportunity. I thank Secretary Hooks for his vision, for–for coming to me with this. And I will just tell you personally, that's something I've always been really concerned about, knowing that my son can't communicate for himself, and he's–he's tall. He's a big boy. He's–he's a young man now that's 23, but he's still my baby. But he–he would look like someone who wouldn't necessarily have any sort of disability. And so if he's in a situation where he becomes agitated or frightened, how would that be perceived by a law enforcement officer? Would they, um, would they mistake it for aggression or, you know, non-compliance? So, to do this type of training is something that is really very near and dear to my heart and pun intended because it really is about keeping all people safe. So, I'm very, very thankful.

Kirsten: You said that Secretary Hooks introduced you to Dennis.

CDS Hoekstra: Umm-hmm. That's correct.

Kirsten: Okay. Has your relationship kind of grown since the initial meeting?

CDS Hoekstra: It has. I am very, very fond of Dennis. He and I've become friends through this process. So, it's been I guess since 2020 that we begin, and he's–he's just a great

guy. He's got a great sense of humor, just a real joy to be around. Fun guy. But yes, we have–we have developed quite a friendship over the years.

Kirsten: HEART training is put on across the state and has been attended by local law enforcement agencies, Sheriff's offices, university security, EMS, fire chiefs, parents, teachers and others. HEART went on the road earlier this month in April 2023 to western NC, hosting three separate training events in Asheville, Boone, and Charlotte. More than 300 individuals participated across the three sessions. Before hearing from our next guest, here are a few autism statistics.

In 2023, the CDC reported that approximately 1 in 36 children in the United States is diagnosed with an autism spectrum disorder. An estimated 25 to 30% of people with autism are non-verbal or minimally verbal. There is no medical detection for autism. Nearly half of those with autism wander or bolt from safety. Drowning remains a leading cause of death for children with autism and accounts for approximately 90% of deaths associated with wandering or bolting by those age 14 and younger. Some individuals with autism spectrum disorder have self-injurious behaviors to include head-banging, arm-biting and skin-scratching. Now we get to hear from Dennis Debbault, as he provides some background on his autism training that kicked off in the early 1990s and *his* vision for the future.

Thank you for joining the podcast!

Dennis Debbault: I'm happy to be here with you!

Kirsten: I just really want to get an idea of how you started your presentation and traveling around the world to spread awareness, and so what inspired you to start the autism awareness training for first responders?

Dennis: It was lived experience, for sure; the dad of a newly diagnosed three-year-old who was diagnosed pretty early considering it was 1987. So, that experience when autism was much more of a rare condition not found a lot in society. The word had little value and meaning when it was used. As well as learning through lived experiences to have contacts with police when people thought that I was suspicious and that I may be a potential child abductor from a toy store at the mall, or having him suddenly disappear while on family gatherings, perilously walk close to very dangerous drop-offs into the raging Detroit River and places of great height. It drove fear into me, and it put me in search of information that I could educate myself about these risks that we were experiencing and share it then with the police in my part of the country which then was Detroit. And I quickly learned that there wasn't any. That information hadn't been published. People were not talking about it. It was as if these experiences were ours and ours alone. And I wanted to find out if that was true or not. So, my background is as an investigator and a researcher. I had been published and worked on documentary programming since *before* my son was born, so that became a mission: to find out if–if what we were experiencing, other people were, too. And I found out quickly that, yeah, there were many other people, around the

country and around the world who were even back then sharing stories about autism, the people who have it and their interactions with police, public safety and criminal justice professionals.

So, I began that work in 1991 professionally and first wrote about it in 1993. And now all these years later, I think my work has finally caught up with the diagnostic statistics about autism which today are 1 in 36. That's the rate of autism in–in America where back in 1987 it was two to five in 10,000 people. So, those experiences and then the early research set me off on a mission that I wasn't sure about at the time. It wasn't that I set out to travel the world and share this information, but it–it, uh, it rang true. Caught the attention of policing and autism community members, and I was welcomed into training rooms, conferences and traveled to North Carolina and testify at your legislature and create a movie on behalf of your legislature on autism in the criminal justice system. I'm real proud to be back and working with the–the HEART project with the–the Department of Public Safety, and the team is great. Enhancing autism information and getting the word out there is the mission now. I could have never thought that would happen back in the eighties, *ever* in my mind.

Kirsten: In the early days of kicking off your presentation, what kind of reactions and responses did you receive from attendees?

Dennis: Yeah, well, back in the early 90s, it was… The question I want to ask of my audience to start with was, "Has anyone in here heard the word autism before?" And I would get maybe two or three hands out of 100. Now, this is in the mid-90s. These days, I can't even ask that question anymore because everybody's heard the word. Most of my audiences today, for–for the HEART program and elsewhere, consist of people that grew up with family, friends, classmates, neighbors who were autistic and lived in the community. That was not the case back in–in the 80s. Most people have never heard the word and were very unlikely to have had any kind of experience of being with an autistic person.

But those days have, uh, have changed for the better, I might add, and that is probably the most remarkable then-and-now story is the rate of autism has increased so dramatically that now this kind of training has become not only essential, but in parts of the country, around the world, too, it's becoming mandatory because these contacts… I describe them well. These same sort of high-risk contacts still exist, but they're happening to tens of thousands, hundreds of thousands of more people than they were happening to back in the 80s and 90s. We need to help people with autism who need extra help, if you will, who may not be able to communicate as well as you would expect and that may need someone with them to avoid the risks of everyday life out in the community: crossing the street, taking public transportation, making a purchase, if they need help there. As a society, we're getting used to helping people. That's what it's all about: accommodations. We all need a little help.

Kirsten: I know people can't see you, but you can definitely just seeing you tell your story, I can feel and see your–your passion. And this is kind of the kicker question, and it's a simple question, but why is this type of training so important?

Dennis: It–it's important because there's a–there is a higher rate of accidental death where drowning is concerned for some children, teens and less independent adults. There is a higher rate of contact with public safety and policing professionals within this population and related disabilities, disabilities that affect your–your brain, for example, or the neural bond between brain and nervous system. It can affect and drive up those numbers when people might not know what they're or who they're interacting with. What–what they can do to help, and so it's a simple premise really to help improve safety for the people who are vulnerable and at-risk, as well as enhance communication between policing, public safety and folks who are autistic and the people that may be with them. Both sides need to be prepared for these interactions, and it's not a difficult task. It's one that you need to be aware of and then put on your agenda of stuff you got to do in–in these busy lives we live, but it's in a– it's a very important aspect of providing accommodations. Whether it's legal or not, it's just the right thing to do. It's as simple as that.

Kirsten: Do you have a vision or a hope for the future for not only training like this, but training that helps all individuals that may find interactions with law enforcement or first responders challenging?

Dennis: Yeah. I–I think that for everyone involved, these interactions include everybody who's there, bystanders, the person in need (whatever the need may be) the police or other public safety professional, fire, rescue, emergency, medical, even folks on a 9-1-1 call, our telecommunicators, will do well by getting some information for their service about interacting with folks with autism and their interactions. So, I think when we give each other more time to explain ourselves and relax and give more people time to process what we're asking or are requiring during the contact to slow things down, to be aware of the sensory environment. What is what you hear, what you see, what you smell, the touches, the things that you can taste and how it may affect your personal safety or the safety of others.

So, there are things in the sensory environment you can't stop or control. Traffic going by on a busy street–you can't stop it. You can't stop that you're on a bridge and you're on a place of great height. So, but there are things that you can manage, and that's typically something that we all do without giving it a second thought, but you–we all need to sometimes just give more time to people that might need it. And it'll–the longer you're with them, the more it'll make sense to you.

And then, communicating really simply: this isn't the time for jokes, colloquialism, figures of speech, slang, words that have more than one meaning. We could be much simpler than that. And don't be afraid to make a mistake.

You know, us humans, you know, we can rebound pretty quick. We're pretty resilient. But given enough time, space, keeping things simple, managing the environment you're in. If you can just focus on those four aspects of interacting with another person you that you don't necessarily know, we'll all do well by the tips, the advice that work for autistic people work for everybody. Just have to give them a chance.

Kirsten: My last question is, what advice would you give to a new parent of a child on the autism spectrum?

Dennis: Very much the same advice for interacting with people you don't know. Give it time Give it space. Yes, you need to be concerned about the near future, but also, it's fair and reasonable, I would advise you, to think about the future 20, 30, 40 years down the line. Think about when you're not going to be around anymore, and what is really important in these relatively short lives we're going to live. And that would be, again, giving people more time and space. Sweat the big stuff. If your five- or six-year-old, three-year-old autistic child is doing something that as an adult will get them into trouble, then that's something you might want to consider working on when they're young and flexible and–and you can make a difference.

So, there–there are certain simple things that when looked at the prism of the future and the distant future, even, that you can get a load of. As well as get involved in the Autism Society of North Carolina. Reach out to your other families who are going through, experiencing what autism is like every day through your child or your family–family member, brother, cousin whoever it may be. And through being with each other, we can start seeing some things that we have in common.

It's not unsimilar than my experience back in the 80s of having risk suddenly appear in–in our daily lives without any warning, and it was the kind of risk that could take a life. So, we shouldn't be mute about that. Let's talk to each other. Let's not let that isolation that can be part of having disability be the ruler here. No, we're not going to let that rule. I get that it can be isolating, socially isolating, but we–we can make opportunities to fit in, be there, show up. Because autistic people are more like us than not. They want to do the same things we do: work, contribute, have fun, enjoy themselves, play music, the arts, make friends, even though it may be more difficult to do. It's not like autistic people don't want this. Give them a chance. Learn what they–what they like, and try to provide it whenever you can, within reason, and don't be afraid to make a mistake.

Kirsten: Thank you so much for sharing all your stories. That has been very insightful. Anything that you feel is, like, really important to share?

Dennis: I think I hit on it earlier, but if you're in North Carolina, and you're listening to this, reach out and join in with–with the autism groups and/or form one

yourself. That's okay. So, you can interact with other people. Get out there into the community.

I would say, be prepared for… Have a safety plan in place. It's tough thinking about the worst things that life brings to you, but the more you do it, the less daunting it seems, and it's really preparing for something that may not ever happen. We do this every day in our lives. So, having a plan in place and practicing it would be something I would highly recommend.

I–I realize that it's not just the police that need to manage the risk. We do, too, and when both sides during these interactions are prepared for the interaction, they *will* go much more safely.

Kirsten: If anyone wants to see any of the materials that you've put out, where can they find that?

Dennis: At Autism Risk Management, put those words together, and then dot com. So, it's autismriskmanagement.com. And through there, you–you'll be able to reach out to me through email. Or NC Department of Public Safety. They'll know how to get ahold of me.

Kirsten: When not on the road presenting his autism response training, Dennis resides in Florida with his wife and son. Anyone interested in learning more about the HEART program with the Department of Public Safety and upcoming sessions can visit ncdps.gov and type HEART, h-e-a-r-t, in the search bar.

Conclusion

Kirsten: This is the Safety Scoop, a podcast written, produced and edited by the NCDPS communications team. The mission of the North Carolina Department of Public Safety is to safeguard and preserve the lives and property of the people of North Carolina through prevention, protection and preparation. Follow the department on social media for a closer look at ongoing initiatives and resources. We're on Facebook, Twitter and Instagram at NC Public Safety.

A special thanks to Dennis Debbault for joining the podcast virtually. Statistics in this podcast were pulled from Autism Speaks, the Center for Disease Control and Autism Risk Management websites. If you enjoyed today's episode, be sure to subscribe to the Safety Scoop on your favorite podcast app. I'm your host, Kirsten Barber. Thanks for listening.

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