

On Deck with PECC+ - Rachel Kripke-Ludwig & Dr. Clarissa Kripke Pt 1

Interview [00:00:03] Welcome to On Deck with PECC+. My name is Darha Patel. My pronouns are she/her, and this is a podcast series in conjunction with the UNC Chapel Hill Department of Emergency Medicine's Pediatric Emergency Care Coordinators Plus program, and a capstone team with the Master of Public Health at UNC Gillings School of Global Public Health. Our goal with this podcast series is to highlight how emergency care providers can provide better care to patients of various marginalized backgrounds. This particular first few episodes will focus on disability specifically. Today we have Rachel Kripke-Ludwig and Dr. Kripke here to talk about respectful and effective care for people who don't use speech reliably to communicate. People communicate in many ways, as we know. So, for example, writing pointing to letters or pictures. Sounds. Sign language. Voice output devices. Body language. Yes/No switches, and more. Some people use gestures, hand leading or facial expressions, or even crying to communicate. Running away or drawing near can also be a form of communication. A C or augmentative and alternative communication is any form of communication that isn't speech. People with speech disabilities are often presumed to have intellectual disabilities or to be incapable of making decisions. They use emergency services more often than the general population, so it's important for us to learn how we can provide the best care possible. So before we meet our guests, I just want to share that our focus will be mostly on Rachel and Dr. Kripke experiences as a whole for patients with disabilities because we felt that it would be helpful to apply these strategies and information to patients of all ages.

So it's time to meet our guests. Rachel is a non-speaking, college bound autistic advocate. She attends Open Mind School in Menlo Park and is a community partner in the Aspire community based Participatory Research Group. The group is working on a five-year project to develop tools to measure outcomes for adult autism services. She's also on the Community Advisory Council of Communication First, the only nonprofit organization dedicated to protecting and advancing the civil rights of people who cannot rely on speech to communicate. Dr. Clarissa Kripke is a clinical professor of Family and Community Medicine at the University of California, San Francisco, and she directs the Office of Developmental Primary Care, whose mission is to build the capacity of the health care system to serve transition age youth and adults with developmental disabilities. She is a primary care physician to some of the Bay Area's most medically fragile and behaviorally complex patients. She also sits as the vice chair of the Board of Communications First, the nonprofit whose mission is to advocate for the rights of people for whom speech is not reliable communication. Hi, Rachel, you're pointing to letters on a letter board held by a trained communication regulation partner who was saying your words out loud today we're practicing patience. ACC, or Augmentative Alternative Communication is slow. If anyone feels impatient, please notice that feeling and think about it. So, Rachel, can you tell us about why communication is important in an emergency?

Rachel [00:05:06] C O M M U N I C A T I O N communication I S C R I T I C A L L Y I M P O R T A N T communication is critically important I N A N E M E R G E N C Y in an emergency B E C A U S E because I N A N E M E R G E C Y because in an emergency.

Dr. Kripke [00:06:05] And it. No, go ahead.

Rachel T H E I N F O R M A T I O N because in an emergency, the information I S S O M E T H I N G is something O N L Y T H E P A T I E N T is something only the patient.

Dr. Kripke [00:06:51] Oh, something only the patient who. One is something only the patient...

Rachel [00:07:06] Y E S S O R R Y yes, sorry I W A N T T O C O N T I N U E I want to continue S O R R Y F O R T H E B R E A K sorry for the break T O D A Y I A M D E M O N S T R A T I N G today I'm demonstrating H O W how I A M W H E N I M N E R V O U S today I'm demonstrating how I am when I'm nervous.

Dr. Kripke [00:08:12] Go ahead. Keep going. You're great. Go ahead. Mm hmm. Mm.

Rachel Y O U S A and s e you can see I see A and C. Oh, and you and I see a T e you can see I can communicate. B y o u t and o t but not a l w a y as w h e and and e r the U

Dr. Kripke [00:09:02] s, but not always when nervous.

Rachel [00:09:07] Keep going. My look. OK. OK. I a

m a n o t, t, r y i and G T o p r o t e s

Dr. Kripke [00:09:30] t, I'm not trying to protest

Rachel [00:09:33] b u t y o u s e t h a t i t h r e w, but you see that i through and y. A r d. I threw my board a C R O as s t h e

Dr. Kripke [00:10:00] across the

Rachel [00:10:01] R o, but you see

Dr. Kripke [00:10:03] I threw my board across the room.

Rachel [00:10:06] I a am I am p u l s i v e I'm impulsive e v e and. W, h e and even when I a m, t, r, y, i and G, even when I'm trying t o c o o p e r a t e, even when

Dr. Kripke [00:10:36] I'm trying to

Rachel [00:10:37] cooperate, I'm. See, so you and I see a T I O and communication. I a s h a R

Dr. Kripke [00:10:51] D communication is hard.

Rachel [00:10:56] F, o, r and E.

Dr. Kripke [00:10:59] Communication is hard for me.

Rachel [00:11:01] E a s p e. C I A L, L Y, especially W, H E and especially when I am and O T F E E L I and G W e l

Dr. Kripke [00:11:23] I, especially when I'm not feeling well.

Rachel [00:11:26] B u t, I see A and

Dr. Kripke [00:11:31] but I can.

Rachel [00:11:35] On it and a k e, but I can make the E C I as i o and

Dr. Kripke [00:11:47] as, but I can make decisions

Rachel [00:11:49] a and d d i r e c t m. Y L, I, f

Dr. Kripke [00:11:59] e and can direct my life

Rachel [00:12:01] on it. See, no. You and I see a T i o and communication. I as c r i t l
see a l l

Dr. Kripke [00:12:21] y communication is critically.

Rachel [00:12:24] I am p o r t a and

Dr. Kripke [00:12:28] T communication is critically

Rachel [00:12:30] important. I and e e r g e and C i e e s is critically

Dr. Kripke [00:12:41] important in emergencies.

Rachel [00:12:43] B e c a u s e because. Oh, and why? Because only T H E P E R S O,
and

Dr. Kripke [00:12:57] because only the person

Rachel [00:12:59] w i t h w i t h a d a s a b, i l i t y

Dr. Kripke [00:13:11] because only the person with a disability.

Rachel [00:13:14] K., A., W. S. knows. T h e i r knows there. I and T e r and

Dr. Kripke [00:13:26] a l knows their internal

Rachel [00:13:29] e x p e r i e and C e s

Dr. Kripke [00:13:36] because only the person with a disability knows their internal

Rachel [00:13:40] experiences and c a r e. G I V E R s caregiver's h a v e. G o d and fo r
a t i o and

Dr. Kripke [00:14:02] caregivers have good information

Rachel [00:14:04] A and D y o u s h o u l d and you should a s k t h e and you should
ask them. F o r a d, b, i, c e and

Dr. Kripke [00:14:24] you should ask them for advice.

Rachel [00:14:27] B U T, I, T, I, s

Dr. Kripke [00:14:31] and T, but it isn't

Rachel [00:14:34] a as you b as T i t u t

Dr. Kripke [00:14:39] e, but it isn't a substitute

Rachel [00:14:42] f o r t a black eye

Dr. Kripke [00:14:46] and g for talking

Rachel [00:14:48] t o y o u r p a t, i e and T,

Dr. Kripke [00:14:58] but it isn't a substitute for talking to your patient.

Rachel [00:15:01] D i r e c t y directly. And why see oh, you and I see a T, I, O and I as a s
l o w,

Dr. Kripke [00:15:23] my communication is slow.

Rachel [00:15:26] A s I h a v e l e a R a n d e d, so I've learned t o p e v e r y. So I've
learned to be v e r y e f f i c, i e

Dr. Kripke [00:15:46] and T, so I've learned to be very efficient.

Interview [00:15:51] Thank you for sharing that, Rachel, do you have any tips for how to
communicate with AC users?

Rachel [00:15:59] Y e s t h a r a yes, Dara T, h a and K a s f o r a s k i and

Dr. Kripke [00:16:13] G Yes star. Thanks for asking and it.

Rachel [00:16:19] P e, p, a t e and T be patient A and D, D, O and T. If I and I, as we

Dr. Kripke [00:16:33] age and don't finish

Rachel [00:16:35] as E and T E and C

Dr. Kripke [00:16:38] E s and don't finish sentences.

Rachel [00:16:43] A K e as you r e. Make sure you dress. T h, e p, e r, s o and I a s d o
and

Dr. Kripke [00:16:56] make sure the person is done

Rachel [00:16:59] s o i k e. And why? C r p.

Dr. Kripke [00:17:07] Like my communication regulation partner

Rachel [00:17:10] s h o w e d, y o u and O W

Dr. Kripke [00:17:16] like my communication regulation partner showed

Rachel [00:17:18] u now on it as h e a d e s u r e she made sure i. As a D, a I I. And why

Dr. Kripke [00:17:37] she made sure I shared all my

Rachel [00:17:40] T H O U G H T s on my thoughts on. C, U, T, T and G as o e o and eo f f e a r l y cutting off someone early c a and can o e a d t o c o and f you as i o and can lead to confusion. A L s o d o and T t r y. Also, don't try t o t o u c h don't try

Dr. Kripke [00:18:27] to touch

Rachel [00:18:28] t h e p e r s. Oh, and

Dr. Kripke [00:18:34] don't try to touch the person's

Rachel [00:18:36] D e v i c e s devices. W without that p e r a m l a s a s i o and without permission? Go ahead. T h a t i a s r u d e that's rude and. T r y t o p q u i e t try to be quiet A and D and o t g e t try to be quiet and not get an e r v o u

Dr. Kripke [00:19:30] s and not get nervous.

Rachel [00:19:33] W i t h a w k W. A R D with awkward as i l e and c e s

Dr. Kripke [00:19:45] try not to get nervous with awkward silences.

Rachel [00:19:51] T r y t o j u s t l i s t e and just listen A and B you as E A. R. A. L and use normal on the O i c e and use normal voice d o and T G, o i and T o don't go into. B. A. B y t a.

Dr. Kripke [00:20:27] OK. Don't go into baby talk

Rachel [00:20:30] and of D don't go into baby talk mode o r or u a s e t h a T or use thatp a t r o and i z, i and G on it t, o and

Dr. Kripke [00:20:49] e or use that patronizing tone.

Rachel [00:20:52] T h a t p e o p l e you see that people use w h e A. A, L, K I and G T, o c, h, i l d r e and

Dr. Kripke 00:21:12] that people use when talking to children

Rachel [00:21:19] and o w, d, o and e now done.

Interview [00:21:25] Thank you for sharing that, Rachel. Do you have any tips for how to communicate with AC users?

Rachel [00:21:32] E the E R Y O and E C O U and I see a T e as everyone communicates a and B C o p e r a t e s and cooperate b e t t e r.

Dr. Kripke [00:21:58] Everyone communicates and cooperates better

Rachel [00:22:01] w h e and c a l when com o y o u r c a l your com d e e a and o r
your calm demeanor. H e l p s

Dr. Kripke [00:22:23] your com d

Rachel [00:22:24] name your com.

Dr. Kripke [00:22:26] The Nemer

Rachel [00:22:27] helps o t h e r a s t h i and K a s t r a i g h t

Dr. Kripke [00:22:38] helps others think straight

Rachel [00:22:40] a s o y you see A and b e e f f e c. **Dr.**

Kripke [00:22:51] T i v e so you can be effective.

Rachel [00:22:56] I am M. O T W E L L R e g u l a t e d. I'm not well regulated. T o d a
y. I'm not well regulated today. B u t y o u w e r e, but you were. S T, R O and G L Y, but
you were strongly. C a l,

Dr. Kripke [00:23:34] but you're strongly calm a

Rachel [00:23:36] and D P, a T, E and T you are strongly calm

Dr. Kripke [00:23:42] patient

Rachel [00:23:43] A and d f l e x i b l e inflexible a and d i w a a s

Dr. Kripke [00:23:55] and I was

Rachel [00:23:57] a b l e t o r e a s you e and I was able

Dr. Kripke [00:24:04] to resume

Rachel [00:24:05] t h e i and T e r v i e w

Dr. Kripke [00:24:11] and I was able to resume the

Rachel [00:24:12] interview. T h a t i s g r e a t, m, o, d, e, l, i and G. That's great
modeling y o u. W e r e p e r f o n it, e c t u r perfect. The show and then.

Interview [00:24:49] Thanks, Rachel. You gave a lot of really great points about
communication and really great perspective, too. So I want us to shift now to talking more
about managing this regulation since you just talked about regulation, actually. Patients
aren't always calm and able to communicate in an emergency. How do you assess the
situation? Can you explain the difference between like a tantrum, a meltdown fight or flight
responses or mental health emergencies?

Rachel [00:25:17] T and T r u. S tantrums. A R e s o c i a l a m a and I P U L A T i o
and

Dr. Kripke [00:25:33] tantrums or social manipulation.

Rachel [00:25:37] I if I if I. See our Y if I cry A and B C A R Y oh, and if I cry and carry on C A and i g e t w h a T, can I get what i w a and T? Can I get what I want on it? I G and o r i and g p ignoring t a and T r u as ignoring tantrums. O R. T, e l, l i and G T H E P e r and that as o and

Dr. Kripke [00:26:30] or telling the person

Rachel [00:26:33] t o a s t o

Dr. Kripke [00:26:35] p or telling the person to

Rachel [00:26:37] stop at a y w o r k may work. B e c, a u s e, because T h e y a R e i and C O and T r o l because they're in control o f t h e s e l v e s because they're in controlof themselves. M, e l, t, d, o w and S meltdowns. A r e. O the e r l o a d meltdowns are overload. T h, e p, e r s

Dr. Kripke [00:27:33] o and the person.

Rachel [00:27:36] C A and T F O L L O W

Dr. Kripke [00:27:42] the person can't follow

Rachel [00:27:43] the I R E C T I O, and as the person can't follow directions, b e c a u s e t h e i r b r a i n because their brain i s o v e r l o a d e d

Dr. Kripke [00:28:08] because their brain is overloaded.

Rachel [00:28:12] T h e why d, o and T and o t i c e o t h e r

Dr. Kripke [00:28:24] s they don't notice others on

Rachel [00:28:26] that a and d a y and may. H, i t t h e s e v

Dr. Kripke [00:28:41] e s and may hit themselves

Rachel [00:28:44] o r o r or are you and l and T o t h e a s t r e e

Dr. Kripke [00:28:56] t or run into the street

Rachel [00:28:59] b e c a u s e t h e y because they a r e and T and c o and t r o l

Dr. Kripke [00:29:13] because they aren't in control.

Rachel [00:29:16] E L T D O W and s meltdowns r e a s p o and

Dr. Kripke [00:29:25] D meltdowns respond.

Rachel [00:29:28] T o t i e meltdowns

Dr. Kripke [00:29:31] respond to

Rachel [00:29:32] time t h e y d o and T g o o and they don't go on f o r e v e r they don't go on forever. W a T T H E M O U T wait them out. K e p t h e p e r s o n and as a f e

Dr. Kripke [00:30:04] keep the person safe.

Rachel [00:30:06] B, why a K and G by making as you are e by making

Dr. Kripke [00:30:14] sure

Rachel [00:30:15] c o p

Dr. Kripke [00:30:16] s by making sure cops.

Rachel [00:30:19] O r o t, h e R s or others as T a y a W a y stairway A and D and J U s t and just w a i t f o r i t, t, o b, e d, o and e, and just wait for it to be done on t h e y you as you a l l y they usually o a s t a m i and u t e s they

Dr. Kripke [00:31:07] usually last minute

Rachel [00:31:09] t o a and. H o u r they

Dr. Kripke [00:31:14] usually last minutes to an

hour.

Rachel [00:31:17] B U T T H e y d o n t g o o

Dr. Kripke [00:31:24] and but they don't go on

Rachel [00:31:27] f o r v e

Dr. Kripke [00:31:30] r, but they don't go on forever.

Rachel [00:31:36] F i g h t o r f l i g h t. Fight or flight. R e a c, t, i o and s fight or flight reactions. C A and B e t r i g g e r e d can be triggered. B, y t h r e a t.

Dr. Kripke [00:32:08] As can be triggered by

Rachel [00:32:09] threat, R., E., A., L. A and D. I am a G I and E D can be

Dr. Kripke [00:32:20] triggered by threats real and imagined

Rachel [00:32:22] and it. P e p, l e w i t h. T r a u m a people with trauma. H i a s t o r i e as people with trauma histories see a and. H a v a t h a T R e a C. T i o n can have that reaction. W, H E and O T when not T h r e a T E and e d were not threatened, the O and T T R a p p e o p l e don't trap people. A. and D. G I v e as P., A., S., A., A. D. T I a m e

Dr. Kripke [00:33:34] and give people space and time.

Rachel [00:33:40] P a s y c, h i a t r i c psychiatric e m, e r g e and C i e s psychiatric emergencies. A R e e i t h e r r either a t h r e a t t o

Dr. Kripke [00:34:10] r either a threat to

Rachel [00:34:12] T H E P E R S

Dr. Kripke [00:34:15] O and to the person

Rachel [00:34:18] o r o t, h e r s or others on a and d a r e c a u s

Dr. Kripke [00:34:30] e d in our caused

Rachel [00:34:32] b y by d e p r e a s a s i o and by depression, p a s y c, h o a s i s
psychosis o r o t h e r or other E A. A., L, H e a, l, t,

Dr. Kripke [00:35:01] h or other mental health.

Rachel [00:35:04] P, r, o b, l e.

Dr. Kripke [00:35:07] Or other mental health problem?

Rachel [00:35:10] T H E Y A Y and e e d they may need. P a s. Y. C h a t r y.

Dr. Kripke [00:35:29] They may need psychiatry.

Rachel [00:35:32] E x, p e r t s

Dr. Kripke [00:35:36] they may need to psychiatry

Rachel [00:35:37] expert T O H e l p to help A and the M A and why c o and. You and
l. T I E s and many communities, h a the E P S Y C age have sake e m e r, g e and

Dr. Kripke [00:36:08] C, why have psych emergency

Rachel [00:36:11] t e a

Dr. Kripke [00:36:12] as psych emergency teams

Rachel [00:36:15] w h o c a

Dr. Kripke [00:36:17] and who can

Rachel [00:36:19] a s a f e l

Dr. Kripke [00:36:21] y who can safely

Rachel [00:36:24] t r a and s p o r t

Dr. Kripke [00:36:28] who can safely transport

Rachel [00:36:30] a s R o m e o and e

Dr. Kripke [00:36:34] who can safely transport someone

Rachel [00:36:37] to a hospital to a hospital. Where where they can and get help. Those situations.

Dr. Kripke [00:37:10] Those situations

Rachel [00:37:12] are a little different.

Dr. Kripke [00:37:21] Those situations are a little different.

Rachel [00:37:24] than disability. From development, and T from

Dr. Kripke [00:37:44] those situations are a little different than disability from development. A L from developmental

Rachel [00:37:53] is as

Dr. Kripke [00:37:55] uses from developmental issues.

Rachel [00:37:57] Like autism

Dr. Kripke [00:38:02] like autism

Rachel [00:38:04] or other cognitive.

Dr. Kripke [00:38:20] Other cognitive.

Rachel [00:38:23] Disabilities

Dr. Kripke [00:38:28] or other cognitive disabilities.

Interviewer [00:38:37] That was awesome. Sometimes people need emergency treatment and struggle to cooperate due to anxiety, movement issues and confusion. Could you talk about medical stabilization?

Rachel [00:38:53] And E.D., I see a Medical as TAB, I L I Z, a T I O and

Dr. Kripke [00:39:04] medical stabilization

Rachel [00:39:06] I as HEL, P I and G is helping a person

Dr. Kripke [00:39:16] and is helping a person

Rachel [00:39:18] with amove and T with movement disability

Dr. Kripke [00:39:36] ty with movement disability.

Rachel [00:39:38] To stay still to say still in good for. Procedure. As for procedures, keep going. Go ahead. OK, go ahead, restraint

Dr. Kripke [00:40:12] and T restraint

Rachel [00:40:14] i as. P h y as I see a l l y is physically h o l, the l and G as o m e o and E is physically

Dr. Kripke [00:40:33] holding someone

Rachel [00:40:34] a g a and as t against T H E I R W I L L

Dr. Kripke [00:40:44] is physically holding someone against their will

Rachel [00:40:47] on R e as T R A and T l as D A and G e r o u s

Dr. Kripke [00:41:00] restraint is dangerous.

Rachel [00:41:05] A and B as H O U, L D and T, B, E, D, O and E and shouldn't be done. You and the E R and O R A L under normal C. I. R C U. S T A and C e as and

Dr. Kripke [00:41:32] shouldn't be done under normal circumstances.

Rachel [00:41:36] E D I see a L Medical R e as t r a l

Dr. Kripke [00:41:44] and T medical restraint

Rachel [00:41:47] i as as o m e t, i m e s and e e

Dr. Kripke [00:41:54] d e d medical restraint is sometimes needed

Rachel [00:41:59] t h a t i as that is g i, v i and G and e d l see a t i o and

Dr. Kripke [00:42:13] that's giving medication

Rachel [00:42:15] t o h e l p c a l to come as o e o and e to come someone

Dr. Kripke [00:42:27] d o w and to calm someone down.

Rachel [00:42:31] F o r a. P r o c e d u r

Dr. Kripke [00:42:38] e to calm someone down for a procedure

Rachel [00:42:41] that i as o m e t i a m e s i sometimes and e d i sometimes need an e d i see a l r e s t r a i

Dr. Kripke [00:43:03] and T i sometimes need medical restraint.

Rachel [00:43:08] O R. As T a b, i l a T, i o

Dr. Kripke [00:43:17] and or medical stabilization.

Rachel [00:43:20] T o d e t c a r e to get care. I T H e l p s i f i f e e l, it helps if i feel a s a f e it helps if i feel safe a and D. K., A., W., A., P. O P L E A R e t, r y. l and

Dr. Kripke [00:43:54] I know people

Rachel [00:43:55] are trying T O H E L P E

Dr. Kripke [00:44:01] A. People are trying to help me

Rachel [00:44:03] and the O and E. Done.

Dr. Kripke [00:44:09] Do you have any other final thoughts you wanted to share or anything else that you'd like to say before we wrap up?

Rachel [00:44:16] T y f o r t h e. Thank you for the o p p. Thank you for the opportunity. T o. E, you see a TV, thank you for the opportunity to educate T h e. P, e c, c, c, o m u and I T Y thank

Dr. Kripke [00:44:47] you for the opportunity to educate the tech

Rachel [00:44:50] community on that y o u r w o r k your work i a s e x t r e e l y is extremely. V a l u a, b l e is extremely valuable. A and D I, H O P E and I hope t o m e t, y o u and i hope to meet you. I and p e r a s o and and I hope

Dr. Kripke [00:45:30] to meet you in person

Rachel [00:45:31] as o m e d a y and

Dr. Kripke [00:45:34] hope to meet you in person someday.

Rachel [00:45:38] H E A L T H P R O F E S S I O N A L S health professionals A R e d, o i and G T h e h a r d are doing the hard w o r k are doing the hard work a and d t h e d i s a, b, i l i t y and the disability c o m a m you and I T Y and the disability community. T, h a and K i s y o u and the disability community thanks you.

Interview [00:46:46] That concludes part one of our conversation with Rachel Kripke Ludwig and Dr. Clarissa Kripke. Please be sure to check out part two of this conversation, as well as the other episodes of On Deck with PECC+. We want to thank our guests for their time and expertise. And thank you for listening.

On Deck with PECC+ is a podcast which aims to educate pediatric emergency services providers on important community topics. It is created in collaboration with the University of North Carolina at Chapel Hill Department of Emergency Medicine. The Pediatric Emergency Care Coordinators Plus Program and the UNC Gillings School of Global Public Health.