

Parents Are Hard To Raise S03 Episode 127 Transcript

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[00:00:37] When you hear the phrase family caregiver hardly anyone pictures an 8-year old, but it's estimated there are millions of caregivers ages 8 to 18 in the United States alone and they are all but invisible. But thankfully that's changing. This week on Parents Are Hard To Raise, Dr. Connie Siskowski founder of the American Association of Caregiving Youth and Christa Haanstra of the Change Foundation in Ontario, Canada join Diane for an eye opening discussion you don't want to miss.

[00:01:08] Join 180 million monthly subscribers who can now listen to Parents Are Hard To Raise on Spotify.

Diane Berardi [00:01:28] Welcome to Parents Are Hard To Raise... Helping families grow older together without losing their minds. I'm elder care expert Diane Berardi.

[00:01:37] What's it like to take care of multiple family members at age 15? Due to an ever growing need, the lack of professional caregivers and limited financial resources family caregivers have become important members of the health care team. When we think of caregivers we typically picture adult family members or close friends. However surprisingly, today's caregivers can also be children as young as eight years old. In the absence of available adults more and more children are being asked to sacrifice their education, health, well-being and childhood to provide care to a loved one. After discovering that one in four middle and high school students in Palm Beach County were academically impacted by caregiving, Dr. Connie Siskowski decided it was time to do something about it. She founded the American Association of Caregiving Youth based in Boca Raton, Florida, here in the U.S.. Dr. Siskowski is here along with Christa Haanstra of the Change Foundation in Ontario, Canada to talk about the role of the youth caregiver. Connie, welcome to Parents Are Hard To Raise. And Christa, Welcome back.

Dr. Connie Siskowski [00:02:53] Thank you.

Christa Haanstra [00:02:53] Thank You.

Diane Berardi [00:02:55] We're so happy that you're here and Parents Are Hard To Raise family you'll remember Christa from episode 111 where she introduced us to the amazing work going on at the Change Foundation. And to our new listeners... Be sure to listen to that episode in our archives.

[00:03:11] So Connie, tell me what happened that led you to the work you guys are doing in Florida.

Dr. Connie Siskowski [00:03:18] Well when I was in middle school I took care of my grandfather as his health declined and I was the one who found him no longer breathing when I went to give him his medication at 2 o'clock in the morning.

Diane Berardi [00:03:32] My gosh.

Dr. Connie Siskowski [00:03:33] And it was... No one really you know talk about trauma and children at that time. Years ago.

Diane Berardi [00:03:41] Sure.

Dr. Connie Siskowski [00:03:41] And so it really impacted my life later.

[00:03:46] And that's one of the things that we see that the trauma that the kids experience today may come up in a year or two years or even more. So when I was remarried and went back to school to get my PhD. this was my research project. I didn't really intend it to be, but once we learned the data I just had this overwhelming feeling of being compelled to do something about it.

Diane Berardi [00:04:19] It's unbelievable when I learned the statistics we just are not aware of youth caregivers.

Dr. Connie Siskowski [00:04:28] Well the work that they do is really behind closed doors. So you know why would you be aware? It's nothing. We're supposed to be taking care of children they're not supposed to be taking care of us.

Diane Berardi [00:04:39] That's right. It's so true. And I suppose their parents, grandparents everyone's living longer. I mean it's just... It's just kind of a domino effect.

Dr. Connie Siskowski [00:04:49] Right. And because we have more grandparents raising grandchildren because of the opioid issues as well as more single parent households. And what happens when that single parent gets sick? And you know also with the mobility of families you don't have that cultural support that we used to have.

Diane Berardi [00:05:12] Yeah.

Christa Haanstra [00:05:15] In Ontario what we also see is that the siblings of those with developmental disabilities.

[00:05:22] Because again of the medical advances some of those people who may have not lived as long as they do now. The siblings are having to step in and provide that care when their parents no longer can or have passed on themselves. And so that's also a piece of the young career puzzle.

Dr. Connie Siskowski [00:05:40] It's complex.

Diane Berardi [00:05:42] Yeah. It boggles my mind. I mean you know trying to piece this all together. How do you define a youth caregiver?

[00:05:51] Well it's any child ages 8 to 18 although the population we deal with primarily starts at 11 years. And they can be providing a variety of activities of daily living including personal care or instrumental activities of daily living. And they do some things such as administering and managing medications that even in our country home health aides are not permitted to do.

Diane Berardi [00:06:21] You're right. It's unbelievable. Do you find it the same in Canada, Christa.

Christa Haanstra [00:06:27] Yeah, we use a similar definition and we actually call them "young carers" here in Canada, drawing from the term that they use in the U.K.. And we see them as young as five and we certainly find young carers as up to 24. So the idea that when they're transitioning into adulthood that still a young age to be providing that kind of care and support.

[00:06:52] And one of the trends we see in Ontario with young carers is that a lot of them in addition to what Connie mentioned is they play a translation role within the health care system for their parents. So if there new immigrants or they don't, or English isn't the first language of the person they're caring for. It's sort of a default role for young carers. And although we see that across all caregivers the number of young carers who do that is higher than amongst the general caregiving population.

Diane Berardi [00:07:22] And you were saying five years old.

Christa Haanstra [00:07:25] Yes. Five years old. And to talk about the complexity one when we talk about that some of the care as Connie said is behind closed doors, but right there's also fear around talking about the role of caregiving in youth because of the possibility for child protection services to be questioning that or whether that could be interpreted as inappropriate. And so it is a complex situation because it's invisible but also there is fear about talking about it publicly as well.

Diane Berardi [00:08:00] I can imagine because the parent for instance or the child will be afraid they'll be removed from the home.

Christa Haanstra [00:08:06] That's right. There is that fear.

Dr. Connie Siskowski [00:08:07] Yeah exactly. There's that fear and at least in the US there's also that immigration fear. So and but so many people just don't understand. So that's why this program is so important.

[00:08:20] We met with one congress person in our office to try and educate him and he said, Well children shouldn't be doing this. You know they should be in foster care.

[00:08:30] And it's just out of ignorance and not understanding that with support they can do so well. And that children we work with are in the highest what we call levels of responsibility. So they spend at least 20 hours a week and typically do one activity of daily living in their work.

Diane Berardi [00:08:54] I can't even imagine you know getting up. You know they have to get up so much earlier go to school. I mean they probably can't do sports or after school activities and come home. And they probably, while they're in school they're worried about what's going on at home.

Dr. Connie Siskowski [00:09:10] Exactly. And there is a commercial that said... It was for a security system and it said, you know when you're worried about what's going on at home it's impossible to learn or think about anything else. And I said, That's our kids.

Diane Berardi [00:09:23] Oh my gosh such a burden. I can't even imagine. I mean what you're doing is remarkable for these kids because they had to feel isolated.

Christa Haanstra [00:09:36] One of the interesting stories we have here in Ontario is a young girl who told her story in the media. And it ended up getting quite prominent coverage in our national paper. And her art teacher at school read the story and said to her, Oh is this why you don't come to our after school art club because I know you love art. And this young girl said, Absolutely I can't go after school I have to go home. And so that teacher switched the art club to Fridays at lunch and something as simple as that allows her to be involved in art as her passion with other kids, when she couldn't before. And there are things that are as simple as that, that can make such a big difference. And of course there are fundamental policy and awareness and understanding issues that need to be tackled as well. But it's not all... It's across a continuum of things that can happen to make a real difference for these young carers.

Diane Berardi [00:10:35] Oh yeah.

[00:10:38] Connie... What do we know about the numbers of youth caregivers in the US?

Dr. Connie Siskowski [00:10:43] Well I wish we knew more. The only national data we have that showed that there were at least one point three million children was released in 2005. And then there was a study funded by the Gates Foundation called "the silent epidemic," released in 2006 and it showed that among young adults who dropped out of school 22 percent said it was to care for a family member.

[00:11:06] So not only is academic underachievement or dropout a concern within grades up through high school but also it's a factor in college incompleteness. So with Christa you going up to age 25 you can perhaps help in that population.

Christa Haanstra [00:11:33] In Ontario which is one province within Canada, we have three point three million family caregivers and of those 17 are between the 17 percent or between the ages of 15 and 24. So that's the stats we have. But as we just talked about a number of the stories we've already talked about the youth are younger than 15 and we do not have statistics for those under 15 for multiple reasons but we know that this is a huge underestimate of the number of youth who are involved in some kind of caregiving.

Diane Berardi [00:12:07] Yeah.

Dr. Connie Siskowski [00:12:09] And thankfully in the United States finally the military is taking a look at children as caregivers of military families. So they're looking at some data. So we'll have better estimates. And also in Florida there is a study that is called the "Youth Risk Behavior Survey," that's really under the I guess the motherhood of CDC. And that was administered in the spring of this year so to middle and high school students. So we'll have a better estimate of prevalence at least in Florida which can then hopefully be extrapolated to other states in the United States.

Diane Berardi [00:12:55] Tell us about the work you're doing in Florida with the caregiving youth in schools.

Dr. Connie Siskowski [00:13:01] So we identify the kids beginning in sixth grade. They take in an eligibility screening and then we meet with them individually once we determine that they're in the top three of five levels of responsibility, so that we can use our limited resources wisely. And then we do skills building groups. We have a curriculum that we've copyrighted that goes from sixth grade through high school as well as we do "Lunch and Learn" sessions so that each month we use a different topic according to the top diagnosis

of the care receivers to provide not only the children in our program but others and school staff with information that they need. Because you know you can imagine that if a family has issues with substance misuse that they're not as likely to get parental consent to for their children to participate. And so in addition to working with the schools we also do a home visit with families that will allow us to and look for ways that we can help the family relieve stress and therefore relieve stress on the child. And we provide fun activities so we have an overnight camp then either fun and educational things so that the kids have time to be a kid because they miss out on that, as we had said, many become isolated.

Diane Berardi [00:14:34] Yeah.

[00:14:37] We're going to continue talking with Christa Haanstra of the Change Foundation and Dr. Connie Siskowski of the American Association of Caregiving Youth. But first, if you're a woman or there's a woman in your life there's something you absolutely need to know.

[00:14:52] I want to tell you about my friend Katie. Katie is a nurse and she was attacked on her way home from work. She was totally taken by surprise. And although Katie is only 5 feet tall and 106 pounds she was easily able to drop her 6 foot 4, 250-pound attacker to his knees and get away unharmed.

Katie wasn't just lucky that day. She was prepared.

In her pocketbook, a harmless looking lipstick, which really contained a powerful man stopping aerosol propellant.

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Darkness brings danger. Murderers and rapists use darkness to their advantage. We all know what it's like to be walking at night and hear footsteps coming at us from behind. Who's there? If it's somebody bad, will you be protected? Your life may depend on it.

My friend Katie's close call needs to be a wake up call for all of us. Myself included. Pick up a Lipstick Bodyguard and keep it with you always.

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Alexa [00:17:21] Getting the latest episode of Parents Are Hard To Raise. Here it is from my heart radio.

Announcer [00:17:26] It's as simple as that.

Diane Berardi [00:17:28] You're right Dolly. There are so many really cool new ways to listen to our show. It's hard to keep track.

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[00:18:12] Connie I was wondering... Obviously this is not just a problem in Florida. Are there any other states doing work like you were doing?

Dr. Connie Siskowski [00:18:22] Ah, Yes. They're beginning to. As we began and started sharing some of the information, people from other states had reached in. And so we formed an affiliate network. And that network is growing.

[00:18:36] One of our more recent affiliates is in Philadelphia at Temple University where they're expanding the services of their Intergenerational center.

Diane Berardi [00:18:47] OK.

Dr. Connie Siskowski [00:18:49] We also began the Caregiving Youth Institute. And through that we have a caregiving youth research collaborative and it's under the leadership of Dr. Betsy Olson of UNC, Chapel Hill and myself. And her program down there is called "Book and Caregiving" and it's about children caring for older adults. Arizona and other places are getting on board.

Diane Berardi [00:19:13] Anything in New Jersey?

Dr. Connie Siskowski [00:19:16] Yes, actually. There's a couple of things. One is called "Hope loves company" and that's a disease specific organization. That's why we work with looking at children caring for a family member with ALS, and the "Family Caregiver Resource Network." So they've had a couple of conferences as has Brookdale foundation that helps with the Respite. So kids need respite too.

Diane Berardi [00:19:43] I was going to ask that.

[00:19:45] Yeah I was going to say because I know there's respite for adults taking care of maybe their parents or whatever so there is a kind of respect for children.

Dr. Connie Siskowski [00:19:57] Well, we provide respite. And it depends... See one of the issues in our country is that all of the National Family Caregiver Support Program dollars flows... It was attached to the Older Americans Act signed by President Clinton in 2000. So those dollars are funneled through the Department of Elder Affairs. And you know so that the tsunami of adult family caregivers kind of outweighs the children. So we really need to raise their children's voices and get legislation to support them.

[00:20:32] And there is a congressman from Pennsylvania who is interested in working with to write our bill on behalf of teen caregivers.

Diane Berardi [00:20:43] That's wonderful. I guess I can see that.

Dr. Connie Siskowski [00:20:47] And I understand it. But children are important to invest in. Not only are they our future but we need health care workers in the future. And if these children are supported properly in their role, then a lot of them want to go into health care, and it makes total sense.

Diane Berardi [00:21:07] Oh definitely.

Dr. Connie Siskowski [00:21:08] So there's a workforce development component, also.

Diane Berardi [00:21:11] What kind of work is being done in Canada to support the young caregivers.

Christa Haanstra [00:21:18] Yeah. So we have also have kind of a variety of programs across our province but they're very sporadic so they don't certainly don't cover all of the province. And we kind of have a flagship program in our Niagara region which borders right on the US, where they provide similar services to what Connie talked about in terms of camps and resilience building programs and skills building programs and just an opportunity for kids to be kids. And most importantly that peer support, so being able to be in a room of other kids where they don't have to explain anything, why they can't go to social activities or why they don't have the same kind of experiences as other youth or don't go into extracurricular sports or whatever. And so that program has been around for more than 10 years and it's really the flagship program here in our province. But it reaches only within that specific region. And so we've been doing work in this area for the last couple of years and I feel like the tide is shifting in that the awareness is growing around the need to support young caregivers in a variety of ways. And so I feel like I'm hopeful for the future and what that might hold for young carers but there's certainly a lot of work to be done.

Dr. Connie Siskowski [00:22:38] And you know it's so exciting for the children so once they meet other kids in their own circle, it there could even be somebody from across the street because you know they don't go to school and say hey guess what I did for grandma this morning.

Diane Berardi [00:22:49] Right.

Dr. Connie Siskowski [00:22:50] And so then they learn they're not alone in their school. And then with activities with kids from other schools they make such strong bonds between them. And they keep in touch with each other so that's really pretty remarkable.

Diane Berardi [00:23:04] You know when you finally you meet someone else going through the same thing as a kid you have that bond, that has to be so... such a relief to them.

Dr. Connie Siskowski [00:23:15] It is.

Diane Berardi [00:23:15] You know and holding hands with another person, with another kid, and you don't feel so awkward or so... You know, no one knows what I'm going through and isolated.

Dr. Connie Siskowski [00:23:29] These are such good kids and they're compassionate and empathetic. You know they're really amazing with support and without it they can get frustrated and quit. And you know sometimes siblings don't feel like you know maybe an older sibling has left home and we've had this experience where that his younger sister was caring for his mom who was blinded and he got upset with her that she wasn't doing enough.

Diane Berardi [00:23:55] Oh, my Gosh.

Dr. Connie Siskowski [00:23:56] We had to get the police involved. There's so many nuances.

Diane Berardi [00:24:02] Yeah. You don't think about you know...

Dr. Connie Siskowski [00:24:06] And the health care system is unaware, so.

Diane Berardi [00:24:09] Right.

Dr. Connie Siskowski [00:24:09] One day we did a home visit and a grandmother was discharged from the hospital in a wheelchair. And they lived in a mobile home. So our manufactured home and those stoops are high. And so in order for her to get to the doctor or into a vehicle for transportation they had to lift her in and out and show you know part of the discharge planning and awareness in the health care system just really needs to be raised up so that these things are in place for families so that they can succeed and not become isolated and get the services that they need.

Diane Berardi [00:24:47] Yeah that isolation is just, it's heartbreaking.

Christa Haanstra [00:24:52] I think the kids who need us the most are the hardest to find. They're often the ones who are doing the heaviest load of caregiving and they might be in a single parent home. They might be living in a rural region where the only time they would you know kind of have other interaction is at school. And in Canada, at the moment, we don't have a lot of awareness in our schools and so they really do go unseen. And that can be very very worrisome.

Dr. Connie Siskowski [00:25:23] That's why we hope to work with Christa and develop a platform of connectivity so that kids from a distance can really work to support each other.

Christa Haanstra [00:25:33] Diane you should know that this interview together is going to be the start of a good partnership between the two organizations so I'm really excited about that.

Diane Berardi [00:25:42] Oh I'm so glad. You guys are doing such great work and I'm so happy to be you know a help in getting the word out because so many people just don't know you know they don't know. I mean you can look at an adult and not even know what's going on with them. You know someone who maybe can't go out for a drink after work or do things but you maybe have no idea what's going on at home. I can't even imagine for a child.

[00:26:14] I think about Diane or sorry Connie was talking about the school programs and those are incredibly important because I think everything we've talked about in Ontario, our focus tends to be on the interaction in the health care system, but for young carers we know that they show up mostly in the education system and that's the easiest and the best place to interact with them.

[00:26:37] But the other point the other stories we've heard are things like a child who is living in a single family home where the mom has a chronic illness and has had an acute episode of some kind and has called 9 1 1 and the E.M.S. has arrived and they can't bring the child with them in the back of the ambulance. So the child's left at home alone, because there's a policy that you can't have that other person in the back in. And they were too young and yet it was OK to leave them at home alone.

[00:27:06] So you know there's some real awareness building that needs to start.

[00:27:11] And then once we get to a certain level of awareness then it's about building understanding and services and supports to make sure that we're providing the youth carers with the support they need so that they can thrive in the future. Because there is a flip side to the young carers coin which is if you meet these young people you will be absolutely blown away by their maturity, their compassion and their ability to handle crisis and challenges.

[00:27:43] And we want to we want those youth to be our future leaders. So we definitely need to support them.

Dr. Connie Siskowski [00:27:50] And we also need to recognize the trauma that they go through so that as adults that they don't have you know trauma events that could be otherwise prevented and suffering and poor decisions. So the counseling for them and dealing with the issues they face is so important.

Diane Berardi [00:28:09] It definitely is. Thank you so much. On our Web site Parents Are Hard To Raise family's search for the Change Foundation.

[00:28:17] This is Episode 7 in a series. Listen to them all. The incredible work they are doing. This can help all of us, from anywhere in the world. And special thanks to Jocelyn Healy who coordinated all of our special guests from the Change Foundation.

[00:28:37] I hope you got something out of this episode. I know I certainly did. Thank you so much for being on the show. Connie and Christa.

Christa Haanstra [00:28:46] Thank you.

Dr. Connie Siskowski [00:28:48] Thank you so much.

Diane Berardi [00:28:49] Parents Are Hard To Raise family I love getting your e-mails and questions. Please keep sending them. You can reach me at Diane at Parents Are Hard To Raise dot org. Or just click the green button on our home page Parents Are Hard To Raise is a CounterThink Media production. The music used on this broadcast was managed by Cosmo Music New York. New York.

[00:29:07] Our New York producer is Joshua Green. Our Broadcast engineer is Well Gambino. And from our London studios the melodic voice of our announcer Miss Dolly D.

[00:29:17] Thank you so much for listening. Till next time... May you forget everything you don't want to remember and remember everything you don't want to forget.

[00:29:26] See you again next week!