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Helene Marcy: Hello and Welcome to the CSCH Podcast. My name is Helene Marcy, Program Manager for the UConn Collaboratory on School and Child Health, or CSCH. The CSCH mission is to facilitate innovative and impactful connections across research, policy, and practice arenas relevant to school and child health. CSCH serves as a central resource to university and external partners engaged in efforts that inform healthy, safe, supportive, and engaging environments for all children. I invite you to take a look at our website at csch.uconn.edu.

Today I’m here with Sandy Chafouleas and Emily Iovino. Sandy is Co-Director of CSCH and a Professor of Educational Psychology at the University of Connecticut Neag School of Education. Emily is a doctoral student in the school psychology program and a CSCH affiliate. We’re going to talk about a recent study they worked on looking at how the caregivers of children with developmental disabilities view their own self-care when it comes to their mental and physical health. Welcome to you both.

Sandra Chafouleas: Thank you for having us.

Emily Iovino: Yeah thank you. It's good to be here.

Helene: So Sandy, let’s start with you, what prompted you to become interested in this topic?

Sandy: That's a great question because my training is as a school psychologist. So that means that I really have worked more directly with children to improve outcomes. You know, particularly for those students who maybe need extra supports in different areas. And as a school psychologist we know that we're seeing really steep increases in the number of children with developmental disabilities such as autism and attention deficit disorder that are coming into our schools, which means that we have a greater need overall for more intensive and specialized supports. And so we've built the evidence behind what those supports should be for students and that's a great thing. But it also has come with increased expectations regarding providing those supports at home. And so the volume of demand and expectations on family caregivers has increased, but we haven't really paid a lot of attention to how do we support those caregivers, who are mostly female. So my interest really comes from saying, you know, if we want to produce the best possible outcomes for children with developmental disabilities we need to figure out how best to support the needs of the people who are providing that care.

Helene: And Emily, how did you become involved in the project?

Emily: Yeah, so my first year of grad school I became interested in family engagement in schools and how educators can promote parent or caregiver involvement in their child's education, especially for those students receiving special education services. So when Sandy presented the idea for this project at one of our research team meetings and shared some of the background, I was immediately interested in assisting and learning more about this. Because I think at its core, family engagement really requires caregivers to meet a certain threshold of physical and psychological well-being. So I wanted to help with working towards understanding what caregivers need to meet this threshold to be able to be engaged with their child's education.

Helene: Tell us why caregivers of children with developmental disabilities have more stress than other caregivers and tell us about the barriers to their dealing with that stress.

Emily: Prior research has consistently supported that caregivers of children with developmental disabilities have identified time commitments associated with the demands of caregiving as a major source of stress. In addition, dealing with the behavioral challenges or medical needs for their child is also a source of stress among family caregivers. Other factors related to stress among this specific population of caregivers have included financial cost associated with caregiving; relationship strain; the physical demands of caregiving; and perceived social isolation. So for family caregivers of children with developmental disabilities, prolonged exposure to these stressors can really increase the risk for physical and psychological conditions, such as heart disease, cancer, depression, and poor sleep patterns. Caregivers of children with developmental disabilities tend to experience high blood pressure, asthma, and anxiety as a result of the increased stress associated with caregiving responsibilities.

Helene: Sandy, why is it so important that we take caregiver self-care seriously?

Sandy: Yeah, so Emily did a great job summarizing what we know about the barriers and challenges that family caregivers of children with developmental disabilities have. And really the summary of that is that we know that not being able to take care of yourself is connected to stress and well-being. That is, we really do have to be doing self-care—however we define it; however it works for us each as an individual—in order to protect against unhealthy stress and increase physical and mental well-being. Yet all of that research just told us that caregivers have more barriers to being able to practice those self-care behaviors that we need. So it's a real problem and that you know the research also tells us that those caregivers who do practice more health promoting self-care behaviors are better protected from stress and negative effects. So in other words, basically it's really important that we intervene to make sure that our caregivers are practicing appropriate self-care so that they can be healthy and ready to be effective caregivers.

Helene: Now, of course there are different ways to reduce stress and to manage stress. Your pilot study looked into the self-care of caregivers, their current and future goals for health and wellness, and their interest in the use of technology to facilitate self-care. Sandy, tell us about the study and how you went about it.

Sandy: Sure. So the first step to understanding how do we help make sure that caregivers are

practicing appropriate self-care was to just dive right in and figure out—what are the barriers that they're saying; what are their needs; and what are the strategies that they already use that are working? So our exploratory study investigated all of these issues and we did semi-structured phone interviews with a number of caregivers of children with developmental disabilities. And we looked for a range of folks with different demographic characteristics and different caregiving expectations to try and understand: what is the diverse range of barriers needs and strategies?

Helene: Participants described some of the negative effects of caregiving on their health and the barriers to their self-care. Emily—can you tell us about that?

Emily: Sure. So the majority of participants talked a lot about having minimal time to focus on their self-care. They referenced the financial costs of caregiving, feelings of hopelessness anxiety, and being overwhelmed as the major stressors and barriers regardless of whether they perceive themselves as having the necessary knowledge about self-care. So that's really consistent with what we talked about previously—that research has consistently shown all of these things to be major stressors and barriers. And I think a really good example that one of the participants shared with regard to how challenging some of these stressors can be is that this participant said, “I'm in a slump. Unless they have someone come in and intervene with me I don't think I could get out of it.” So really demonstrating, sort of, the gravity of how these stressors impact caregivers.

In terms of some of the financial stressors, another participant shared that, “The financial piece is huge for me. I stress about it all the time but try not to. On the nights I do sleep, I'm thinking about what bills to pay and how to make ends meet.” So really again demonstrating how—across different types of stressors and sources of stress—there are unique challenges and concerns that caregivers have. Some participants also describe barriers related to personal factors outside of caregiving roles such as being a single parent, low socioeconomic status, and chronic health problems. For those participants who talked about being single parents, they discussed feeling isolated and lonely, partially as a result of caring for a child with developmental disabilities. One participant in particular said, “I feel really lonely. Him wanting to go places and people not wanting him to stay because of his condition. Not being invited because of his condition. I have to be careful about who I invite over because of my child. No social life for him and no social life for me.” Participants who referenced challenges related to some chronic health problems also talked about added responsibilities of having to bring their children with them to appointments or cancel their own appointments to care for their children and this really presented challenges in managing their health conditions.

Helene: So given those pretty significant barriers, what are some of the ways they said theydo promote their self-care?

Emily: Yeah so even though the participants talked about a lot of self-care challenges, I think it's really important to note that all participants identified strategies and resources that they use to promote their self-care. For some participants things like going to the doctor for yearly screenings and buying produce whenever possible were endorsed as primary strategies that they used to promote their self-care. One participant, with regard to this, shared, “I always try to keep up with my screenings and make sure that I have a physical every year. I will make time for doctors’ appointments and physical health.” So I think that shows that—even amidst all of the self-care challenges—that many caregivers can still find time to take care of themselves, even if it's just going to the doctor.

Other participants talked about relying on their social networks for support and discussed strategies like talking to family and friends; attending or running support groups; and going to church or practicing their religion or spirituality as self-care behaviors that were really beneficial for them. Some participants even talked about practicing yoga, mindfulness, meditation, and exercise along with going to counseling or therapy as primary self-care strategies. So there was really a range in the type of self-care strategies that caregivers used.

Helene: Sandy, what would you say are the main takeaways from this study?

Sandy: That is a great question. So I think I would summarize it as really under falling

under three takeaways: the first is that you know we found that the majority of caregivers expressed that they did have a need and a desire for some additional strategies, particularly that would target domains of how they eat better; how they sleep could sleep better; and how they could could play better—have more social connection.

The second takeaway, I think, is that there were definitely common barriers—most specifically around the time and the ability to access those resources and have time to do this self-care. And the other was financial. And third, I think we found that caregivers identified that they need to have strategies that include social support. Many participants discussed the strain that being a caregiver has on their relationships with other adults. So we really think that intervention design and strategies should include ways for caregivers to be able to promote their social support, positive relationships with other adults, as a mechanism to facilitating increasing your health promoting self-care.

Helene: So tell us what’s next. This was a pilot study so are there plans to expand this research? And Emily, I understand that your dissertation is focusing on this work?

Emily: Yes it is. So given what we did in this initial pilot study, I really wanted to focus on developing an intervention based on some of these findings for delivery using social media, which can help to remove a lot of the barriers to self-care that we identified. The intervention just finished last month, so I’m working on analyses now but I’m excited to wrap up and share findings with the CSCH audience.

Helene: Thank you Sandy and Emily for joining us today and telling about this pilot project. I look forward to following this to see how we can help caregivers. And let me remind our listeners that you can find information about Sandy and Emily and all of our affiliates at the CSCH website, csch.uconn.edu. You can also follow us on social media @UConnCSCH. Thanks to both of you.

Sandy: Thanks for having us. We really appreciated the opportunity to share our work.

Emily: Yes, thank you.

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