

Episode 121 - Dr. Christina Sogar: Beyond Diagnosis: The Dynamics of Disability and Disruptions in Parenting

[00:00:08] Welcome to in social work. The podcast series of the University of Buffalo School of Social Work at www.insocialwork.org. We're glad you could join us today. The purpose of in social work is to engage practitioners and researchers and lifelong learning and to promote research to practice and practice to research. We're in social work. This is Charles Sims your host at in social work through the looking glass a center dedicated to research training and services to families that have been impacted by disability has reported that there are between four point one and 9 million parents who have a disability. The size and diversity of the number of these families speaks to how important it is to understand their experience. In an effort to better respond to their needs. Our guest is Christina Sogar. At the time of this interview a doctoral candidate at the University of California Berkeley School of Social Welfare. Inspired by her early work as an advocate for adults with developmental disabilities Sogar's research has focused on disability and parenting. In this podcast she will discuss her recent work in understanding the psycho social aspects of parenting with a disability. Ms Sogar was interviewed by Katie Knaak a second year Ph.D. student at the University at Buffalo School of Social Work who has more than twenty years experience in the disability field. Today we are talking with Christina Sogar Christina is a Ph.D. candidate soon to be a graduate of the University of California at Berkeley. And she is here to talk about her research on parenting with a disability.

[00:02:07] Christina the reason that we chose your topic as a podcast is because we really do have relatively few researchers out there talking about individuals with disabilities and the kind of issues that they face. So we appreciate your time if you could start by telling a little bit about your research interest. We can go from there. Sure. In 2010 I was given the opportunity to work with Professor Jane Malden and Dr. Richard Spiegelman on a study investigating the well-being of parents who receive Supplementary Security Income SSI and their children. SSI provides cash aid for people with disabilities. So a little bit of background information in 2013 the federal SSI payment is seven hundred ten dollars per month. Almost all states supplement this amount slightly though. For example in California the federal payment and state supplement combined so that parents are getting total monthly payment of 866. Assume these are for parents that are not getting any sort of other types of disability insurance. So just the straight SSI payment would be 866. So we wanted to learn how well these parents are doing. There's this general perception out there that parents who receive Temporary Assistance for Needy Families TANF may be struggling because they receive less money and live work requirements and time limits but once they transition to SSI there's no more work requirements there's no time limits and there's a little bit more money. However these parents lose what are often essential support such as childcare and transportation assistance. So with the 2010 study really aimed to identify how SSI receiving parents and their children are doing. We found a great deal of material hardship among the parents we talked to as well as child health and behavioral problems.

[00:03:54] So one third of these parents reported high child welfare involvement as well. And so I became very interested in learning more about the caregiving needs and SSI receiving parents what support they find most helpful and the circumstances that triggered the child welfare contact. I see. You started with talking about being invited to participate in the research study. Can you talk a little bit about your own personal interests when it comes to parents with disabilities. Sure I have. In the past before joining the Ph.D. program I worked as an advocate for adults with developmental disabilities and also worked as a counselor and a life coach for adults with disabilities. So it's just always been something that's close to my heart. It's something that I've been very interested in and

then through the Ph.D. program wanted to begin to learn about how families are doing. When the parents of disability on a broader scale very good. Thank you. So what are you doing currently in terms of your investigation that pertains your dissertation. Ok so my dissertation really builds on the 2010 research for my dissertation I revisited some of the parents from the San Francisco study and then also interviewed parents in Alameda County which is like Oakland California. That area. So I had a total sample size of 127 parents. The majority of the respondents were women. In fact 95 percent of them were so I'll probably refer to my respondents as mothers throughout this interview. Almost all of them were single and had lived in their current county for many many years. So my dissertation investigates the parent's health economic and caregiving problems and resources.

[00:05:39] I'm interested in how these problems and resources correlate with specific parenting practices including parenting stress and self efficacy. How they view themselves as parents as well as the likelihood of child welfare involvement. Additionally I'm considering psychosocial characteristics of disability. The title of my dissertation is beyond diagnosis. The dynamics of disability and disruptions in parenting and by beyond diagnosis I'm referring to not just the incapacitation and the symptoms the parents have but also the psychosocial characteristics. So when I am referring to onset of course an expected outcome these come from John Rowland's family systems health model I consider how that course an expected outcome influenced parents understanding of and reaction to their own disability and their relationship with their children. So onset refers to how the disability occurred whether it's acute like a heart attack or stroke if it's more gradual or if it's a result of trauma or injury. Course it's just the stability of symptoms and abilities are parents able to do the same things each day or do their abilities change from day to day. Basically are they able to predict what they're going to be able to do over the next few days in terms of their caregiving responsibilities. And finally I'm considering an expected outcome which refers to whether or not the parent worries that her disability will result in death. So for the parents I spoke with instability of the course of their disability with a tremendous problem for them. One of the questions I asked parents was are there things you're able to do some days but not others based on your health.

[00:07:17] 70 percent said yes to that and the test that most parents reported being able to do some days but not others was get out of bed and that really struck me you know when you've got small children that you're responsible for and your health is so volatile just the stress and pressure that must be associated with that would be very difficult for parents I imagine so are most of the individuals in your study. Mothers of small children no, it varied quite a bit. There were the average age of the children was a ballot 11 but probably only about a third of them had children under the age of five. But many of them had toddlers as well as an older child. Right. And certainly the challenges with children of varying ages. There's different challenges and they'll remain pertinent. I would think to your research absolutely in terms of thinking about how disability affects not just the parents abilities but how it intersects with the family life cycle and the demands placed on the parenting parent so that the parents health is changing you know the needs of the family are also changing. I'm really interested in how those things intersect to affect the relationship that caregiving abilities I see now in your particular study. How was Disability Defined by disability I mean mental health physical and learning disability. As I said I was talking to parents who receive SSI so I use the same definition as the Social Security Administration to qualify for SSI. Applicants must have a disability that prevents them from engaging in substantial gainful activity which is generally defined as earning one thousand dollars or more per month or is expected to result in death within 12 months.

[00:09:05] But in my sample the other thing that I was really taken aback with her I didn't realize coming into this was how often disability occurred among SSI parents or at least the ones in my sample. Most parents over 65 percent reported more than one type of disability. Often it was physical and mental health problems and in fact one in four parents reported working limited in

mental health physical and learning disabilities. While that's quite a bit. Can you tell us a little bit about the health needs of the parents that you interviewed. You know in addition to those issues that were specific to a diagnosis or a disability I'm assuming they also had other kinds of health concerns that might not be experienced by a typical mom. Sure. So along with the mental health physical or learning disability diagnosis I looked at things like pain and to post traumatic stress disorder and chronic pain was widespread 80 percent of the parents experienced chronic pain in the previous six months and pain was which makes sense that pain was correlated with activity limitations including completing household chores and meal preparation. And I think that is related to what I was talking about in terms of course that parents don't know from day to day what they are going to be able to accomplish and a lot of that is related to pain. They just don't know how severe pain whether it's from depression or physical pain is going to be and how that's going to affect the things they're able to accomplish. Also post-traumatic stress disorder was widespread. Over 50 percent either scored positive on a four question PTSD scale or reported past diagnosis of PTSD.

[00:10:55] So victimization and violence was a real problem for these parents and I'm sure it related to their mental health problems. The other thing was I talk to parents about the health needs of their children. And over 40 percent reported activity limiting physical emotional or behavioral problems among their children. And by far the most commonly reported childhood conditions were asthma and mood disorders usually depression as well as developmental disorders. Now do we know how many SSI recipients are parenting minor children. That's a great question. Not exactly official reports from the Social Security Administration do not provide data on parenting rates. So we don't know. We don't have an exact count. However as part of a study on child only temporary aid for needy families TANF cases. Jane Molde and Richard Spiegelman Matt Stogner and I used data from the 2010 American Community Survey to develop an estimate. So we looked at the parenting rate among working age adults with less than 4000 dollars in earnings income less than 100 percent of the federal poverty line who reported work limiting disability and SSI income of less than eleven thousand dollars a year. Basically the people that we could identify with are respondents or SSI recipients. So the turnout rate for that sample was just over 17 percent. If we take that and we apply it to a four point seven almost four point eight million working age SSI recipients we get an estimated of eight hundred 16000 recipients who are apparently minor children. So that would be pretty current information folks out there in these situations.

[00:12:39] So based on what you're telling me sounds like these families are getting a combination of SSI benefits and maybe the TANF benefit to support the young child or children that are in the home but are still living in poverty. What can you tell me about the material and economic well-being. So I asked parents about inability to pay rent and ability to pay utilities as well as food insecurity and overall material hardship is pretty widespread. Twenty two percent of parents reported being able unable to pay their rent in the previous year. Forty eight percent said they were unable to pay utilities and have even had electricity cut off that type of thing. And over one third reported food insecurity that there wasn't enough food and that they or their children were often hungry. And I looked at the material hardships based on different types of health problems and material hardships appeared to be more common among respondents with mental health problems although they were slightly more likely to report problems paying utilities. They were much more likely to report problems with rent or providing adequate food for their families. Were you able to find anything within the data after that would help speak to why that might have been happening. Yes actually I looked at public and private supports and looking at domains supports parents relied on. So Section 8 and also look at how that varied by health problems and that is Section 8 was pretty much evenly available whether or not the parents had mental health problems or not. That is parents with mental health problems were just as likely to report having Section 8 as parents with mental health problems. But parents with mental health problems were much more likely to report having received food from a food bank.

[00:14:33] Fifty percent of them versus 30 percent of parents without mental health problems. So while they were more likely to turn to community support public like a food bank they reported a much lower level of social support from family or friends. So I think that parents with physical disability may have more trouble accessing public supports you know making it to a food bank. But they have friends and family members available to help them. So I think parents with mental health problems may be more socially isolated which may account for some of their economic problems. And I think that's been evident in the literature and the service system is that families tend to kind of distance themselves from folks who have long term mental health issues so that wouldn't make a lot of sense. What did you learn in terms of parenting and caregiving needs. What do these moms need from the system that they're not currently receiving. The parents completed a number of different scales measuring different parenting constructs. So I'll just kind of go through each of these. First of all looking at caregiving limitations completed the parent disability index several parents reported limitations and 40 to 50 percent of basic caregiving tasks based on the ages of their children. Parents reported the greatest difficulty remaining patients attending social outings and playing up upside with their children. So look at some of the co-variet area where the scale I found positive associations between caregiving limitations and the parents level of pain and psychological distress which makes sense that caregiving limitations did not appear to be associated with the age or number of the children. The stability of symptoms was also associated with caregiving limitations.

[00:16:18] Parents who reported more volatility in their capabilities and what they could do on a day to day basis also reported more caregiving limitations in terms of nurturance. The parents reported a higher rate of nurturance and that was pretty much across the board. But I did look at parenting stress and self efficacy and parenting stress was really really widespread which probably makes sense a higher score on the Kesslers Psychological Distress Index so more mental health problems more anxiety and depression are correlated positively with parenting stress. So greater psychological distress was associated with greater parenting stress is also associated with lower self efficacy. So parents had more trouble viewing themselves as good parents when they suffering severe mental health problems. However with physical limitations we're not associated with parenting stress or advocacy. So the mental health problems appear to have more of a relationship to how parents actually view themselves as parenting as parents than physical limitations. That's fascinating. What are the main support the parents relied on. Well I guess probably you'd want to talk about both formal support from agencies and organizations as well as family and social support. And I mentioned Section 8 and section 8. Parents who did have section 8 were much less likely to have problem paying rent or to have food insecurity and other types of support in-home supportive services is available in the Bay Area in California. Many other states as well I believe. And that was a huge support for parents.

[00:18:06] Only about 30 percent had just us but these services allow parents to get to the growth it'll be transportation assistance to the grocery store helping parents with completing laundry and basic household tasks. So parents felt less stress and pressure about household tasks because they had the ISS workers. However at least in California in-home supportive services well they could help parents with disabilities. They cannot help the parents with their children. So let's say a parent has a physical limitation that makes it difficult for her to change the baby's diaper the IHSS worker can help the parent with the parents needs but cannot do anything for that child. And that's something that I would like to see potentially change so that in-home supportive services could be a greater support for parents in their actual parenting role. Right. And I've worked in the disability field myself and we see that in New York State as well. When you talk about in-home support services is that broadly defined or is that a specific funding source in your area. Because here in New York it could mean a personal care aide paid for Medicaid or it could mean Developmental Disability Services paid by a Medicaid waiver program. It's specific. In fact the way the program works is that parents don't qualify for in-home supportive services. They qualify for a certain number of hours and then they are able to interview and choose their own IHSS. They're not just to

sign somebody and that's great because a lot of times parents can choose to friend or relative that they trust that they feel safe with and that can also help bring more income into the family. Very good.

[00:19:58] So I understand that there's been some recent research by Dr. Elizabeth Lightfoot from the University of Minnesota and some others that are beginning to suggest that parents with disabilities are disproportionately represented in the child welfare system. And you mentioned that earlier that you found some of that in your study. Can you talk a little bit more about child welfare involvement among the parents you interviewed. Sure. So as with the 2010 research about one third of the parents in my study reported past or current child welfare involvement. And I've mentioned the psychosocial characteristics onset course an expected outcome. And I found that parents whose disability had an acute or traumatic onset were much more likely have been contacted by child welfare services. It was really interesting to me that I'd like to learn more about is it a trauma that resulted in parent disability that's also bringing CPS into the home. I don't know but I think that's definitely an area for future research. Parents physical limitations positively correlated with child welfare involvement. But mental health problems did not which somewhat surprised me because mental health problems seem to be associated with more caregiving problems as well as economic and material struggles. In my study. But it was not associated with the current physical limitations however were when children had activities limiting health problems the families from much more likely to have been involved with child welfare do you know how that compares to what the general population in terms of how many folks without disability might have found somebody from the child welfare system. It's really a great question that there's not an answer for it at this point. We really do not know about rates of parental disability and child welfare system.

[00:21:49] I know that children with disabilities are more likely to have CPS involvement which is you know what I found with my research but it's really an unanswered question about how are parents with disabilities that personally represented. And what among parents involved with the child welfare system what are the rates of disabilities to the best of my knowledge. Those questions have not been. I would like to say though a part of my dissertation has more of a qualitative focus. And so for the parents that did have child welfare involvement I talked to them about their experiences of the process. Not surprisingly I guess they had a fairly negative impression about having CPS come into their home and they did not feel that their families needed child welfare services. Seventy percent said that child welfare worker did not ask them about their health or their mental health problems that that was in no way part of the interaction. Most of those parents were really relieved by that. They really worried that their health problems and SSI status would bias the child welfare worker against them and result in their children being taken out of the home. So they were not wanting to bring up any of their health issues. They did not want to volunteer any information about their health problems or their economic problems. Only 12 percent of the parents actually felt that the CPS involvement helped connect them to counseling services or material benefits things that they needed. Interesting. So what do you see as the next steps in this area as you continue your research or as other folks do similar types of studies what kinds of questions do you think still need to be answered.

[00:23:25] Well as we just mentioned we definitely need information on prevalence and what percentage of parents involved with child welfare have disabilities. I'd also like to learn more about what public and private support parents find most helpful what do they rely on the most. Our food banks and the essential support section 8 family and friends. What really helps parents complete their parenting tasks. Also I'm really interested in learning more about disability from the child welfare side of things. How do agencies and child welfare workers approach disability. The parents in my study felt that their disability was not part of their conversation they had with CPS workers. They thought this was a good thing because they fear discrimination but it could have prevented the family being connected to helpful services. So I'd really like to learn more about child welfare

workers views of parental disability and possibly even develop training to help workers and supervisors become more aware of and sensitive to disability help prevent discrimination against parents with disabilities and the child welfare system and also help connect them to the three services. So in your study you didn't have any direct connection with these folks. It was all by report of the parents themselves. Now I have most of the parents and almost all 95 percent signed a release which will allow me to access county level administrative data. I'll be getting that information soon and that will help corroborate some of the information that I was told from parents about their child welfare involvement. I'm kind of surprised that that many parents were willing to have you access their information. They were really interested in improving services.

[00:25:14] So the fact that a lot of parents that received the letter about my study chose to not participate. So I think the parents that wanted that were willing to do the interview and help provide this information were also willing to provide administrative data because they were willing to do that interview in the first place. I see. So it's my understanding that you're going to be moving on in your career here graduating and you're heading to University of Nebraska for any. Yes I will be working as an assistant professor there and all. How do you see any opportunities to continue your research in that area. Oh absolutely. All of my research to this point has been in an urban setting. And so I would like to continue to research urban settings but I also like to look for parents in a more rural area. They might not have food banks and more of the public supports that are available in an urban area and what kind of support do these parents rely on. So I'm interested in beginning to look at that as well. Well that should certainly contribute to the field and some pretty interesting ways. Thank you. Well thank you so much Christina and good luck in your future endeavors. Thank you so much you have been listening to Christina Sogar discuss her work on the psycho social aspects of parenting and disability. Thank you for listening. This is your host Charles Sims inviting you to join us next time at in social work. Hi I'm Nancy Smith professor and dean of the University at Buffalo School of Social Work. Thanks for listening to our podcast.

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