inSocialWork Podcast Series

Episode 86 - Dr. Nicole Ruggiano: Doing It Their Way: Consumer-Directed Long-Term Care

[00:00:08] Welcome to living through a podcast series of the University at Buffalo School of Social Work at www.socialwork.buffalo.edu We're glad you could join us today. The series Living Proof examines social work research and practice that makes a difference in people's lives. I'm your host Adjoa Robinson and I'd like to take a moment to address you our regular listeners. We know you have enjoyed the living proof podcast as evidenced by the more than 150000 downloads to date. Thanks to all of you. We'd like to know what value you may have found it in the podcast. We'd like to hear from all of you practitioners researchers students but especially our listeners who are social work educators. How are you using the podcast in your classrooms. Just go to our website at www.socialwork.buffalo.edu forward slash podcast and click on the contact us tab. Again thanks for listening and we look forward to hearing from you. Hi from Buffalo where we just officially reopened Rotary Rinke are free open air downtown skating rink with the lighting of a 50 foot tree. I'm Peter Sobota readers of John McKnight's writing lamenting the professionalism of service delivery and the cost to Clynes dignity motivation and self-determination. We'll recognize familiar themes in our latest podcast. Dr Nicole Ruggiano describes an alternative to traditional agency provided and managed long term home care by detailing the consumer directed care model consistent with other research on cly itself change.

[00:02:02] Motivational enhancement and empowerment practice Dr Ruggianodiscusses a client driven self directed approach to their own care via a voucher benefit given to them or their caregivers. Dr Ruggiano addresses the positive outcomes related to this approach and takes head on the barriers costs and challenges to it. She concludes with a description of her latest research in this area related to decision making strategies for older adults and a call to action for collaborative and empower based practice by social workers. Dr Nicole Ruggiano is assistant professor at the Robert Stempel College of Public Health and Social Work at Florida International University in Miami. She has been recently selected by the John Hartford foundation as a Hartford geriatric social worker. Her research interests are in aging with a focus on consumer directed services and long term home care. She is also interested in client decision making strategies as they choose their own health care services. Doctors Yano also collaborates with F.I. U.S College of Nursing studying an intervention aimed at increasing the communication between home care managers and their clients physicians doctors Yano was interviewed by Dr. Adjoa Robinson assistant professor here at the School of Social Work. This is your host Adjoa Robinson and my guest today is Nicole Ruggiano assistant professor at the Robert Stempel College of Public Health and Social Work at Florida International University in Miami Florida. Dr. Ruggiano thanks for joining us today. Thanks for having me. Dr. Ruggiano you are a Hartford geriatric scholar. And for our listeners who are unaware of that program the Hartford geriatric scholar social work Scholar Program is a program to address the shortage of social work faculty with geriatric experience in the face of this rapidly increasing older population that we're experiencing.

[00:04:11] The title of your proposal is decision making of older adults and consumer directed care. So Dr. Ruggiano exactly what is consumer directed care consumer directed care is a newer model of human services. Traditionally Holeman community based services have been coordinated managed arranged all by agencies and not by the people who actually receive the care. And so there have been a lot of criticisms of that approach because there are many people who have experienced care that did not meet their needs based on the type of services available did not meet their needs because of the time that agencies would schedule care or they did not like the people who were providing care and they had other preferences for who provided their care. So this concept of consumer direction became more popular where basically the care recipient is provided with a

voucher or cash and they are able to decide in many cases what types of services and products they can receive what times they can receive services who provide the services and in many cases people actually use their benefits to pay family members or friends to provide their care. That sounds like something that's right up social works. Allie I imagine we are pretty good at implementing that model. Yeah I mean it really reflects the whole concept of self-determination and dignity of the client so I guess thing that actually benefited when I applied for the Hartford scholarship because it does reflect just the central social work values. You said it's a recent model. When was it implemented and what was the impetus. This became more of an idea I would say around the 1990s. It wasn't until the early 2000s that the consumer directed care model really took shape.

[00:06:11] And one of the things that really sparked it was the Robert Wood Johnson Foundation funded in partnership with the United States Department of Health and Human Services a project called The Kashan counseling demonstration project. This project originally I believe was in three states Arkansas Florida and New Jersey and worked with Medicaid recipients who were receiving home and community based services as part of their Medicaid benefits and it provided them with the option of receiving consumer directed services as opposed to agency directed services. And not everybody is actually interested in this model. So there were many people who still wanted agency directed services. But one of the great things about the demonstration project was that they were quite large and there was a very large evaluation completed and now the Tashan counseling project has expanded into more than a dozen states and some states have implemented their own consumer directed care programs as well. I know that California on their own has had a Medicaid based consumer care program as well. So what has been found is some of the positive outcomes of the use of this model some of the positive outcomes when comparing the recipients in consumer direction to those in agency directed services tend to be higher levels of satisfaction. Fewer reported unmet need better quality of care and some of the criticisms of consumer direction people have been concerned that maybe it would result in lower quality of care or even present danger to the care recipients because here we're not having professionals arrange and provide care but we're having many times family members friends but there doesn't seem to be any greater risk involved with this model as opposed to the agency directed model.

[00:08:10] Some folks are still kind of suspicious about this model. Why do you think that might be. I think first we're taking human service responsibilities that were traditionally done by professionals and we are putting that responsibility in the hands of the care recipient. So one of the larger questions has. Like I said earlier risk. So is there any risk involved another has been fraud. So if we are giving the Kerry Sybian cash sometimes or vouchers and sometimes the terrorists have been due to their limitations stemming from their disability they actually have a representative managed care benefit so they themselves are in there. Somebody else is in control of the cash or the vouchers. And so there are concerns that there could be higher incidences of fraud because currently there really aren't any best practices with quality control to make sure that the cash and the vouchers are being used appropriately. That when a family member is being provided care that they're actually providing the care and not just taking the money and not providing care. Some of that kind of fraud concern about fraud already happens whether it's consumer directed care or not. We've seen endless stories on television about some doctors and others who basically set up a get your medical equipment kind of a rocket just to get extra money from the government. It does happen with all different types of care. I think the concern is that this would elevate the risk of fraud. But I will say that there isn't any research that has been completed that is identified that fraud is a problem or has been a problem. On the other side are there any cost savings to consumer direction.

[00:10:03] It's funny because initially the idea of consumer direction. Many scholars have opposed this idea was great because it would be a cost savings because the consumer is only going to choose the services that he or she wants that any unnecessary services would not be scheduled by an agency who is not connected directly with the Caribbean. But what we actually found in research is

that it's more costly and the only reason it's more costly because when you compare agency directed care with consumer directed care clients in each model might be allotted the same level or amount of services for the person and consumer directed care will receive more of the services that they have appropriated to them. So what that means is that people in agency directed care are more likely to be granted services that they will never receive. So it does raise questions about yes it does increase the cost of Medicaid but it only increases costs because people are receiving the services that they have been allowed to receive. It also seems to at least to me indicate that perhaps through consumer directions folks become more aware of what's out there and are therefore able to take advantage of more of the services that are due to them. Yes.

[00:11:31] You have to be more aware and I have a paper under review I'm one of the arguments that I make is that here we have the role of social work coming into play because what we need now is people in the field of moment can be the services who no longer view themselves as the expert but they view the care of subpoenas the expert and the provider is somebody who provides them with the knowledge the empowerment the ability to go and find all of their options to evaluate all of their options and to utilize all of the options that are available and appropriate for them. Sounds like working in a partnership working as a team. Yes yes it's very much like team is needed. But there are questions about the role of the current consultants and case managers in consumer direction. There have been reports that some of them don't feel that all of their clients are qualified for this model but it's unclear why or if they really are unqualified that sometimes they feel like there is inappropriate decision making and some of them just have reported that they don't feel that that this isn't necessarily appropriate model for people with who are aging or have certain disabilities. What's your feeling on that. I feel that thinking about the concept of self-determination said the client is appropriate in most cases and what my research that I'm conducting through the Hartford really wants to look at consumer decision making. I want to be able to learn about what decisions consumers make what are the basis of these decisions and what factors are involved with making these decisions and evaluating these decisions and by doing so we would actually be able to develop some sort of benchmark for evaluating consumer decision making. So for instance here we have case managers under traditional Medicaid Home and Community Services. They are evaluating the decision making of clients based on what is appropriate for case managers and that might not be the same as the reasons why somebody who is the care is that we would make those decisions.

[00:13:48] You mentioned that the case manager would be looking at an assessment as a case manager. And I guess I understand that it's they have a different perspective from a client has. And so it's necessary to have the clients perspective. Yes. Just stepping back a second. My question about the cost savings around that because of an example we have here in the city of Buffalo a police officer was severely injured and disabled from that injury in the line of duty and was going to require long term 24 hour care and rehabilitation. What the city ended up doing was paying that police officers partner to provide the care. And this was a couple of years ago what they were going to pay that person per year was sixty thousand dollars. Now care in a nursing home is what about 300 dollars a day. I mean it depends on the nursing home. But yes. Yeah. So it seems like it would be a much higher cost to have had that police officer receiving care in a facility versus at home. And I think that's what they figured that the cost savings would be much greater. Right. The cost savings of Home and Community Services will always be less than institutional care. I think what the question is since this case with the police officer is it less costly to pay the police officers partner. Sixty thousand dollars a year then giving them that police officer the ability to access all of the services that are professionally available to him or her where they would have professionals provide care. Day in day out.

[00:15:42] Or what other types of services though is it to give the partners sixty thousand dollars for to give the police officer access to all of the fees fees for services that are available in the community. Yeah I see the sanction there. So costs are always going to be more in an institutional

setting. So there have been documented cases where say we have an older woman who needs care. Say the woman in her 90s and under agency based care agency says OK we're going to provide services to this woman from 8:00 a.m. until 12:00 p.m. Monday through Friday. Now the older woman in her 90s does not wake up every day until about 10:00 in the morning. The family does not see it appropriate to wake her up before she is willing to wake up to dress to bathe to eat to do all of the activities that the agency arranged care would provide. So they that's being paid for through maybe Medicaid or even out of pocket is paying for four hours of care we're only maybe two hours of care being provided now. What consumer directions has done in a case like this would say OK we will pay for four hours of care five days a week. And the woman has the ability to maybe say OK well my granddaughter will provide me with care. So either though my granddaughter will provide me with four hours a day care and I will give her the benefit and she can come from 10 to two. Therefore all four hours that were paid for were received or maybe she only needs care from 10 to 12. And so then fewer services would be accessed and the services that are accessed would be better utilized.

[00:17:41] They would be better utilized. There are cases where we have people that don't speak English people that are older adults that are native Spanish speakers that are even any to any type of language where maybe services professional services are not necessarily available for that person in their native language. And so rather than receiving services from somebody that they can't communicate with they can pay a family member or friend through their benefits to provide their care. They can communicate effectively and therefore services would be more satisfactory to the client and maybe they would even many cases may be more appropriate for the client. Now this model didn't initiate with older adults or application with older adults. I would say that this movement towards consumer direction released them from the disability rights movement which has oftentimes through history separated itself from aging aging and disability rates have really intermingled since the 1960s. But there they're really still is a disconnect and you can see that in consumer direction because this model is viewed as being more appropriate for non elderly individuals with disabilities as opposed to older adults with disabilities. And that was one of the reasons why I became interested in this research project to only look at older adults decision making because there have been cases where older adults have the. And this is documented in research have had the option of consumer direction and not case managers but program coordinators have steered them away from that option because they did not view older adults as being appropriate for consumer directed care. And what is the basis of some of that determination of not being appropriate for the belief that older adults to not direct their own services.

[00:19:38] Is that because of an assumption about diminished capacity yet diminished capacity is the number one belief but also many older adults who have diminished capacity can elect a representative to manage their services. So then in those cases then there is suspicion that there will be increased fraud. So here we run the risk with older adults either. There's suspicion that they do not have the cognitive or physical capacity to direct their own care or they will elect somebody who will direct their care for them who will use the funds inappropriately. So that's one of the challenges of implementing consumer directed care for older adults. What are some of the challenges to get over the ageism or are there other challenges as well. There are obviously challenges out there for older adults specifically in consumer directions but they haven't all been identified. For instance if we compare older adults in consumer directed care with non elderly individuals in consumer direction we find that older adults have lower rates of satisfaction. They also withdraw from programs more often than not elderly. So in cases where there is a plan like many times the client has to come up with a spending plan in place before they receive any benefits. Older adults are less likely to complete that plan. So there's something going on that is putting older adults at disadvantage but that hasn't really been fully explored through research.

[00:21:18] So and so that's what some of what you're going to be doing and your research that is

what I'm going to be doing some of the questions I want to ask is What are some of the barriers to decision making have older adults made decisions with their benefits that they had to change before. Nobody's really asked those questions. So right now what role can social workers play in overcoming some of these barriers. Well first of all social workers have to identify if they themselves hold atheist beliefs about older adults that might be affecting their practice second. Typically in a home and community services people work in interdisciplinary teams to provide care to older adults. So here we have individuals who will be communicating and working with physicians with nurses with homemaker services and other types of support care services and the social worker has the responsibility to reinforce these basic tenets of social work. So I just felt determination Clane autonomy dignity of the client that might not be as emphasized in other disciplines. So these are central points of social work and social work as a responsibility of reinforcing that within the other professions that they coordinate with. So what's the take home message the take home message is that we're going to have a growing number of older adults receiving services many of these older adults will receive their services in home and community settings. And so we need to find more personalized ways of providing this care more appropriate ways of providing this care and consumer direction is a way of doing that. However we need further research and further like increased access to consumer direction in order to do this well recently. Part of the Affordable Care Act was the Community Living Assistance Support Services a class act. So with the Affordable Care Act there was passed the Community Living Assistance Services and Supports Act or it's also known as class act.

[00:23:37] And this actually will promote the consumer directed model for individuals at higher incomes in Medicaid typically. Now this is offered through Medicaid by the CLASS Act is going to establish a long term care insurance program for workers. Bed is voluntary that everybody can pay into. And if you find yourself disabled after contributing for five years you will receive no less than a 50 dollar daily benefit to manage your own care. So I think one of the larger takeaway messages is we as a profession have to really reinforce the tenets of self-determination autonomy and dignity because we're going to have to use them with a larger number of older adults who are in the services we have to learn what clients feel is appropriate for them and not necessarily feel like we are the experts in providing their care. That's a great message and I hope all our listeners take it to heart. Dr. Ruggiano thanks for joining us today. Keep up the good work. And we look forward to hearing more about consumer direction and long term care in the future. Oh thanks again for listening to my research and my interest and I was happy to be here. You've been listening to Dr. Nicole Ruggiano discuss the consumer directed care model approach to long term home care a living proof. Hi I'm Nancy Smyth Professor and dean at the University at Buffalo School of Social Work. Thanks for listening to our podcast. For more information about who we are our history our programs and what we do we invite you to visit our website at www.socialwork.buffalo.edu. At UB were living proof that social work makes a difference in people's lives.