

Episode 31 - Dr. Nancy Kelley-Gillespie and Dr. Karen Rolf: Too Old To Care?: Older Adult Caregivers and Their Children with Disabilities

[00:00:08] Welcome to living proof A podcast series of the University at Buffalo School of Social Work at www.socialwork.buffalo.edu. Celebrating 75 years of excellence in social work education. 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. The University of Buffalo School of Social Work is celebrating 75 years of transforming lives and communities. We would like to invite you to be part of the celebration. Please visit our website at www.socialwork.buffalo.edu to see a full list of events marking our seventy fifth year leading up to the gala celebration. The U.S. population is aging now adults 65 and older make up about 12 percent of the population with a projected growth to 20 percent by 2030. Concomitant to that growth is a call for a shift in services and the development of new services to meet the needs of the growing population of older adults. But did you know that their adult children with disabilities were aging as well. Since the 1970s the population of adults with disabilities living with their aging parents has doubled as is life expectancy for those adults has increased often outliving the capacity of their aging parents ability to act as a primary caregiver. How do we meet the unique needs for safety care and quality of life for families consisting of aging parents and their aging children with disabilities. That's the question for today's guests doctors Nancy Kelley Gillespie and Karen Rolf are assistant professors with the School of Social Work at the University of Nebraska at Omaha.

[00:02:05] Dr. Kelley Gillespie received her Ph.D. in social work with a graduate certificate in gerontology from the University of Utah. Her background and interests include developmental disabilities and aging quality of life and quality of care for older adults end of life care and caregiving issues. Dr. Rolf received her Ph.D. in social work from the University of Chicago in addition to her work as a school social worker. Dr. Rolf has an extensive background in math science and evaluation. Her interests include the effect of children's health on families school social work special education the well-being of children with disabilities and foster care in adoptive homes and the interaction of health status on overall functioning doctors. Kelley Gillespie and Rolf spoke with Dr. Deborah Waldrop of Associate Professor at the University at Buffalo School of Social Work and Hartford scholar by telephone I'm Deborah Waldrop from the University of Buffalo School of Social Work and I will be talking today with Dr. Karen Rolf and Dr. Nancy Kelley Gillespie from the University of Nebraska at Omaha. We'll be talking about older adult caregivers of adult children with disabilities. And before we start I'd like to thank Dr. Rolf and Dr. Kelley Gillespie for joining me today and for offering us the opportunity to learn from their work. Thank you both very much for this opportunity. We really appreciate it. I'd like to start by asking Dr. Kelley Gillespie why the topic of older caregiving of adult children with disabilities is so important for policymakers and practitioners today. Well this is an important topic for policymakers and practitioners as well as researchers for several reasons.

[00:03:51] First we are seeing an increase in the numbers of households comprised of aging parents and their adult children with disabilities. There's an estimated seven hundred eleven thousand individuals with disabilities who live with their family caregivers over the age of 60 in the United States. So we have sort of a dual phenomenon happening. We have a growth in the number of older adults due to the baby boom and a general increase life expectancy. And we also have increased life expectancies for individuals with disabilities especially those with developmental disabilities. So these children with disabilities are now aging along with their parents when historically they did not often live into older adulthood and children with disabilities did not usually outlive their parents. So we also see increases in the number of children with disabilities living with their parents instead of being institutionalized which used to be the more common practice. But in recent decades we have

seen efforts to promote and support more home and community placements. So now what we're seeing is a situation where the adult child with a disability is living their parents capacity to provide their primary care. In fact it's likely that in many of these households both the aging parent and the adult child with a disability are in need of caregiving support. So understanding the needs and the resourcing of both aging parents and their adult children with disabilities in these households is important so that we can make better choices for caregiving and for developing appropriate care plans for each of the family members in the household.

[00:05:40] So it's also significant for determining service needs and how to organize and deliver formal Aging and Disability Services which by the way have not often overlapped until more recently or at least we're trying to get those to overlap more and ultimately we want to be able to ensure that the quality of care and the quality of life of both the aging parent and the adult child with a disability are maximized not only while they're still living together but also if and when the time comes where either or both family members are in need of an out of home placement. So this real demographic shift is really changing the dynamics and these families in many ways. I'm wondering if you have anything that you'd like to share add with that. Dr. Rolf I'd like to add that one of the first concerns about the council is that if the older adult caregiver needs the community placement that misrepresents the need for community placement for the child with a developmental disability as well so that communities are then faced with finding two placements rather than one. So this I think would be a special concern for community planners and policy makers. And then the second thing I think that we are telling Gillespie and I discussed when we've been very interested in is the idea that there may be a reason that these Helsel exist and in these helpful there may be something there's maybe some strength and that there may be reciprocal caregiving going on. We were particularly interested in looking at some of the things that may be going on in this household. And he's helpful. So that was something of interest to us and that may offer that reciprocal care giving may also be of interest to policymakers and planners as well.

[00:07:29] Absolutely I think the notion of the special concerns and the reciprocal caregiving are really interesting dynamics and I'm I'm really mindful of the fact there must be policy and practice implications that arise from these living arrangements in particular I guess for social workers in practice and as you mentioned policymakers I'm wondering if you could identify for us Dr. Kelley Gillespie any specific policy or practice implications that emerged for you. Well I think I noted earlier that some of the practice implications blow relates specifically to the types of services available to both of the parties involved in the household the older adult well as the adult child with a disability what specific support systems we can build into their care plans that will be an important factor to look out of. Wow. What are those needs. Because the needs will vary. You know for the aging parent as well as an adult child with a disability especially as they move across the lifespan and we're really going to have to pay attention to those diverse needs in these households and try to develop the most appropriate and the most effective interventions to meet their needs. Absolutely will be a challenge for social work practitioners and educators alike. Doctor Rolf I'm wondering if you could talk a little bit about how the living arrangements of older adults and their children with disabilities has changed in the United States since 1970. Certainly to look at this question. We used census data and then we use data from the American Community Survey we use census data from 1970 to 2000 and then we use the American Community Survey from 2000 to 2004. And what we see like other researchers is that adult children adult children regardless of their disability status aren't moving out of the home of their parents.

[00:09:24] So whether you have a disability or not you're less likely to move out you're more likely to live in the home of your parent. You can see a lot of that is written in the media and some shows you know adult children move either they don't move out or they move back in with their parents. But what we see is that for this trend for adult children with disabilities is even more significant. In fact since the 1970s the number of adult children with disabilities has doubled. Who live in their

parents home. So after telling us because we estimate in the United States and other researchers estimate is about seven hundred eleven thousand of these parents who are caring for adult children with disabilities. So we see that this rate is increasing it's increasing at an even faster rate and it's increasing by age group as well. So if you are in age levels of 35 to 44 that's your age rate for an adult child with a disability. The percentage of these children in their parents households is increasing an even faster rate in parents homes. So these children who are in adults and are disabilities and their parents homes are even older than what we would expect. Wow. So the boomerang generation as I've heard it referred to I guess in the media is having its effect on children with disabilities as well. It's really across all parts of our society. I'm wondering Doctor Rolf if you could talk a bit about the kinds of disabilities that are most commonly found in adult children and the older adults who are living together.

[00:10:59] We see that the developmental disability such as mental retardation are most likely to be found in their parents homes. We use a survey of income and Program Participation. Another data set to look at the specific disability. What's also interesting is that when we compare the disability of the older adults and the adult children we find that older adults who have orthopedic problems are more likely to care for adult children with orthopedic problems. Now we're not sure in those cases what came first. You can imagine that caring for a child who has an orthopedic problem over years maybe also stressful on your own body you know. So in those cases we can do some examination and lead us to future research questions. But there seems to be relationship between the type of disabilities that are found in homes. If you have an orthopedic problem you're more likely to have an orthopedic problem yourself. We also see that another common disability that we find in homes is mental illness. Adult children with disabilities who are living in their parents homes were also older adults tend to have mental more mental illness. It really strikes me that the kind of disability that you're describing are really quite varied and depending on the nature of the disability the dynamics in caregiving and just what people face in caring for each other in that reciprocal caregiving relationship are going to be really very different. I'm wondering Dr. Kelley Gillespie if you have anything else that you wanted to share about that are the thoughts about the disability that are that you're seeing. Actually I think Dr. Rolf has something to think.

[00:12:44] I'd like to add also that when we find homes when there are two caregivers so we have both a mother and a father present is both of us caregivers have disabilities. The probability that this child in the home will also have a disability is about five times as great. So we see that there are certain homes where disability is much more likely to be present and that there's this very interesting that you don't really know what's going on in the homes but that if we don't know if it's why these homes have so much disability but that with both caregivers have disabilities are more likely to have a disability and a child. Or it could be that. So we're not exactly sure why this is happening. It's really important to search for the answers to that and future research it sounds like for sure. Dr. Kelley Gillispie I'm wondering if you can talk a little bit about the caregiving arrangements that you find in these households. What we find basically are two types of caregiving that happening in these households. So the first kind is where the older adults are the aging parents are providing the primary care to their adult children with disabilities. And then the second type is where the adult children with disabilities are providing care to their aging parent. So aging parents are more likely to provide the primary care for example assistance with activities of daily living to their adult children with disabilities. Although the level of care may vary by the type of disability that the adult child has.

[00:14:27] So for instance more than 70 percent of adult children with developmental disabilities and about 63 percent of adult children with behavioral disabilities have their aging parents of their primary care provider compared to about 30 percent of adult children who have a biomedical or an orthopedic disability and only about 40 percent of those adult children who have something disability. So it's also interesting we found it interesting that the findings from our study showed

that about 23 percent of the adult children with disabilities in this sample anyway reported that they provided care for their aging parents and that compared to only about 10 percent of the nondisabled adult children who were living with their parents. In our sample. So in a period of no more of the kids with disabilities were providing care for their peers and the disabled kids. And we found that was a point of interest to look out further. So overall I guess the findings that we have suggested there might be like Dr. Rolf indicated earlier some reciprocal caregiving taking place within the household and this reciprocal caregiving might be a great strength to the functioning and the longevity of these living arrangements. It could be a way that family systems adapt to changes across the life course and meet their goals. I mean including you know aging in place which is usually the preference of people anyway to stay together keep their families intact and to stay in the community for as long as possible. And it might be a way also to provide a sense of purpose or motivation for the different family members.

[00:16:21] So learning more about these reciprocal care dynamics might offer a source of social capital to foster and promote within the service delivery system or if these reciprocal caregiving relationships show detrimental effects to the health or the mental health outcomes of the family members then maybe a different approach or modifications might be needed within the service delivery system to maximize the outcomes for both the adult child with a disability and their aging parent caregivers. Your work is really profound. I just think this is such an important topic area to be looking at and I just think there are so many implications for as you say the service delivery system social workers and a variety of different health and social service arenas and I'm just really I'm really impressed by what you've done and I'm thankful that you're working in this area. I bet that you have also a lot of thoughts about the kinds of medical services that are used by these household and I'm wondering if you could talk a little bit about that Dr. Rolf. We've looked briefly at the hospitalizations that are utilized by these families and what we find is that aging parents who are the primary caregivers of adult children with disabilities have significantly more hospitalizations per year compared to aging parents who just have adult children living in their households when they're not the primary caregiver. So we see that they're using hospitalization more. In addition those hospitalizations tend to be reimbursed so that they have more medical overall. So something's going on in those phones with respect to their overall health. But again this is more of you know we we put controls in for overall income and all kinds of things that something's going on and some of these households where even though they may be getting some reciprocal care we don't think the quality of the care that they're getting in the home is quite enough.

[00:18:25] And so we need to look more closely at that and I'd like to add to that we've taken some pretty rough cuts at the data so far. So for example when we find that older adults are the primary ADL assistant for their children only 30 percent of the time when they had orthopedic impairment. That may vary a lot by age. So for example they meet these adult caregivers they do that for a long period of time but as they get into their 70s and 80s it they decline and if we look at Dr. Kelley and I have looked at that more closely by age because it may. You know when we look at people in their 60s they may be the primary HDL and then drop off. So when we examine these ADL assistance knee you know we see significant differences by age and at the same time. We've talked about the typical caregiving and examining that by you know adult children who don't have disabilities but they may be employed outside of the home and maybe maybe bringing money into the household rather than caregiving for their parents. And so we've talked about expanding it that way too. So we've got a lot of work to do. We just have taken some initial steps at our day. So I just wanted to add that I appreciate that I now have just I'm sure so much more to tell us about the needs and the issues that are faced by these families and their loved ones in the future. And it's just those as I said it's just really important work and thank you for that for all that you're contributing we really have we stand to learn so much from this work.

[00:20:04] I want to ask each of you if there are other issues that we should talk about if there's

anything else that you'd like to add to the topic of older adult caregiving and adult children with disabilities as we close. Dr. Kelley Gillespie anything else that you'd like to add. And in summary our conclusion here. Well I think the Dr. Rolf did a great job of trying to laying out part of our future research agenda. And some of the other things that we're interested in as far as our research goes. But I do think that there are a lot of different ways to look at this information and implications of the situation. You know not only as far as how we can support people in their homes but what happens after their aging parents is not able to take care of them at all when there is a placement out of home or if they die. You know what's going to happen to these adult children who are now also aging with a disability. What does that really mean for our service delivery system that are not prepared for this and all we have in either camp services if you will the disability services sector and the aging service sector we have massive shortages of services and issues that we need to deal with to serve either one separately let alone blending the two systems together and finding ways to work efficiently and effectively. You know for both of these populations whether the parents and children are living together or even living apart or as the children with disabilities enter into the aging service delivery system too. There's a lot of things that we need to address.

[00:21:58] Absolutely. Any other thoughts or final ideas that you'd like to share with us. Doctoroff I would like to add to that the question of caregiving of adult children with disabilities and older adult caregiving is an even though it is a historical one. You know even though we're just looking at it right now from 1970 to 2004 it's something that and it seems more it is more poignant because older that it is people with disabilities are living longer longer longer ages. We've had this question in our country for a while. And I'm interested in what families have done in the past as well and I think there may be ways to look at you know what siblings have done. The questions that people the decision making that they make and I want to I would like to go back and we talked about going back and looking at census data even further back to see some of the trends that have been we've seen in some of the in the caregiving practices that we've had. And then some of and also some of the ways to answer this question might not be with the census or the survey Income and Program Participation of the American Community Survey that we've talked about using some qualitative data very interested in that. Dr. Kelley Gillespie's specialty to get some of these decision making the decision making that parents and families go through that will be really important in the future. That sounds so very nuanced and that with the qualitative approach should really be able to delve down deeper and sort of find out what's behind these statistics even so we really appreciate your time today.

[00:23:50] And I just want to thank you both for your willingness to participate in this podcast series and for sharing this really cutting edge work with us. Thank you. Thank you for having us. We really appreciate the opportunity. You've been listening to an interview about older adults and their aging adult children with disabilities with doctors Kelley Gillespie and Rolf from the University of Nebraska at Omaha. Tune in again next time for more lectures and conversations on social work practice and research. Hi I'm Nancy Smyth professor and dean at the University at Buffalo School of Social Work. Thanks for listening to our podcast. Our school is celebrating 75 years of research teaching and service to the community. More information about who we are our history our programs and what we do. We invite you to visit our Web site at www.socialwork.buffalo.edu. At UB we are living proof that social work makes a difference in people's lives.