

Episode 75 - Dr. Elizabeth Lightfoot: Parents with Disabilities and the Child Welfare System

[00:00:08] Welcome to LIVING PROOF 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. This is your host Adjoa Robinson and I'd like to tell you about a new feature we have at the Living Proof podcast series and that's the listener comment line. You can call us at 7 1 6 6 4 5 3 3 2 2 and leave a comment or suggestion. And who knows maybe in a future podcast we may feature your comment on the air. The number again is 7 1 6 6 4 5 3 3 2 2. Call us. We'd love to hear from you. This is your host Adjoa Robinson. Most of us are familiar with state child welfare statutes that govern termination of parental rights. Typically they include issues of child abuse and neglect. However what if one of the criteria for parental rights termination was simply because you have a disability. What would the impact be on your family and your child. Today's guest Dr Elizabeth Lightfoot wanted to know the answer to that question. Dr. Lightfoot is an associate professor and Ph.D. program director at the University of Minnesota's School of Social Work. Dr. Lightfoot has over 20 years of experience working with individuals with disabilities and examining disability policy and services.

[00:01:52] Over the years her primary research focus has evolved from studying antidiscrimination policy to studying how disability policy and the concept of accessibility intersect with other social service areas such as child welfare. In today's podcast Dr Elizabeth Lightfoot speaks by telephone with Savra Frounfelker Ph.D. student at the University of Buffalo School of Social Work about her research efforts to improve the lives of people with disabilities. My name is Shavar and this is Liz from the University of Minnesota. Liz would you like to tell us a little bit about what you're working on right now. Sure I'm happy to. I've been for the past 20 years generally looking into disability and policy and disability policy and services and lately I've been looking at the intersection of disability policy and services and the child welfare system looking both into how children with disabilities and parents with disabilities interact with the child welfare system. What's your most recent work in that area. Lately I've been focusing mostly on parents with disabilities and sort of came about where we were working on a project for relooking at the intersection of kids with disabilities and child welfare and looking at the state statutes and realized that parents with disabilities were actually listed in the state codes where disability was listed as a grounds for termination. In most of the states they didn't give any specifics in that realm or just if you have and I know you know most of the state statutes are pretty vague and written pretty broadly. But disability was one of the only conditions that's listed in the state statute. So usually they are focusing on parental behavior as grounds for termination like neglect or abuse or things like that. But disability is listed not singularly. So a lot of codes say disability alone can't be looked at as grounds for termination.

[00:04:09] But in the context of other things you can look at a parental disability coming from a disability rights and advocacy background. This just struck me as something that is way off base. We should be focusing on the behaviors of parents not whether they have a disability or not. And if you put disability directly into the state code then that will make the child welfare system and especially the courts focus on disability. And there's a little bit of research showing that that is what happens where people will focus on you know let's see if we can get a diagnosis and if we have two psychologists say they have a disability and that will end up being grounds for termination. So we are looking at that and thinking well you know it just really isn't making a whole lot of sense for how we generally support people with disabilities in the disability world. The big concept parental support and parental support on supports in general individuals supports the general idea. So we

look at what kind of support whether they're formal and informal can help people with disabilities live in the community things like education and supported employment. All sorts of areas to see how people with disabilities can be fulfilled their major life domains. The one area that we usually don't think about as being a major life domain is parenting for people with disabilities. Now most states have some kind of system set out for people with disabilities to provide supports. Do you see at least in Minnesota that there are any services in regards to parenting. Very little.

[00:05:55] Most state all states have pretty extensive support systems for people with disabilities and people with disabilities through the Medicaid waiver or through DD services can get support for living in the community working in the community transportation those sorts of things. But what it doesn't include is for parents with disabilities. Any help for them with their kids. A person with a disability could get support let's say they could get accessible transportation they could have the van come pick them up and take them somewhere but they wouldn't be able to take their child on the van with them. We need to step back a minute and because you're talking about parents with disabilities are you specifically looking at developmental disability or did you look at all the Yeah you know I tend to take a broad view of disability and use the 88 definition which covers you know most people who have limitations and one or more areas but often the focus becomes on people with intellectual and developmental disabilities and parenting. Even though parents with sensory disabilities or parents with physical disabilities has often been discriminated against in court proceedings where a parent with a disability who's let's say going through a divorce a parent with a physical disability a disability will be brought up as something to focus on. And many parents who really have very few limitations have had trouble when they interact with the courts around parenting. So my research has focused both specifically on folks with intellectual and developmental disabilities as well as more broadly on disability in general because the services for the different disability is different. They vary quite a lot. The notion of supports that really comes out of intellectual and developmental disabilities.

[00:07:45] And AAIDD the American Association on Intellectual and Developmental Disabilities has made the concept of support sort of a cornerstone of their view of disability and it's really been groundbreaking that the view that people with intellectual and developmental disabilities need supports just like everybody else and these courts are crucial for having them live more included lives more inclusive life. So when it's been your research in that area aside from the policy research which has been very interesting when we are looking at the policy research so sort of tell you the story a little bit so we are looking at the policy and looking at how parents with disabilities are being treated in the state statutes. We ran across an advocate from Idaho who had been very interested in removing the disability language from the state code and they actually after a multi-year process of advocacy got the Idaho state code to change. And in the process they said that when the courts were looking assessing parents with disabilities they had to look at what types of supports or assistive devices that they'd need to help parent their child. And so that's where the idea of parental support came about. But then we realized we didn't really know what parents with disabilities actually need to support their children. So that's where my partner and I so I work quite extensively with Tracy Law Liberty who's in the Center for Advanced Studies and child welfare here at the University of Minnesota. And so we partner a lot on these projects and we thought that if we're going to put parental support into these state codes and more and more states now are starting to do that.

[00:09:35] So we've had in the last couple of years we've had two or three more states put in the concept of parental accommodations and parental supports in the state codes then we need to figure out what these actually mean specifically for people with disabilities so if a parent with disabilities is involved in the child welfare system what should they be looking out for supports. What are the formal and informal supports that parents might need and really every parent needs supports. I have three kids and I have had child care for them so that was one of my parental support. I paid for it

myself. But the idea that parenting is not a completely independent activity but it's rather an interdependent activity. So grandparents providing respite care is a form of informal support that many people have if they're lucky. Well isn't child welfare now looking into providing parental support supports even past people with disabilities. The child welfare system does do some of that. But generally when they're assessing whether someone is able to parent their child they're looking at whether they're able to independently parent their child and that has been the big problem for people with disabilities particularly people with intellectual and developmental disabilities. Some of them may be able to provide lots of the parenting but not all of the parenting they might need help with certain things. And that's not considered acceptable in the child welfare system. So that's what the problem is so we're trying to broaden the idea that when you're assessing a parent you have to look and see what are their broader supports and these can be things for someone with a physical disability like adaptive equipment.

[00:11:12] You know there's all sorts of adaptive cribs or child care equipment or it can be someone who's serving as a parent mentor or providing respite or coparenting or things like that as well help with homework or tutoring. So that's the research that we're working on right now is we're trying to figure out what are the typical parental supports that parents with disabilities need. And so we're in the midst of a research project right now where we're interviewing parents with intellectual and developmental disabilities in sensory disability and physical disabilities. Essentially asking them what are the types of parental supports that they need that they receive and then for those that they receive how effective they are. And so that's where in the process of doing that right now I think we've interviewed about 30 folks so far and are getting some preliminary findings about what are the services that people typically get. So it's a qualitative study the qualitative study we're doing in-depth interviews but we're also actually asking them to rate services and discuss which services a need and want. We're also looking at parents who have been directly involved in the child welfare system and asking about their involvement with the child welfare system. What sort of modifications that some Americans with Disabilities Act language what modifications the child welfare system is made to make their services accessible to parents with disabilities. Do you have any preliminary hearing. It's nothing really surprising but part of why we're doing this is to get sort of a baseline so when the child welfare system or the courts are looking at parental support they have an idea of what types of parental support to look at.

[00:13:11] By far the types of supports that people want and get and find helpful are informal supports like parents coming over to help them grandparents coming over to help them. Those sorts of things that would be probably for every parent those would be the most desired you'd rather have your family members coming over to help you than some paid staff person coming over to help you. Parents with disability thought that they needed and they thought that they were helpful were things like parenting classes that were tailored to parents with disabilities daycare respite care accessible transportation. These are the types of supports that most parents would like but these are ones that parents with disabilities find particularly helpful modifications to child welfare parents with disabilities found particularly helpful. The two main things were having hands on parenting instruction and in-home parenting instruction so the parents live intellectual and developmental disabilities particularly don't do very well if they go to a parenting class they would rather have someone come into their house and show them directly you know what to do in this particular situation which makes sense since they need a little extra attention than a class would give them right. And also that's how some folks learn better as they learn by they learn by doing and the transfer of knowledge is easier when you're actually doing it in your house with your own kids and having someone watch you do it and then provides you tips and pointers on how to do it better. Now does Minnesota does this system for people with intellectual disabilities provide independent living support for somebody to come out and do those kinds of things. There are independent living services but again they're not focused on parenting activities.

[00:15:08] So these are usually coming through the child welfare system. So if you need help with parenting you only get that if you've come to the attention of the child welfare system which is not a good way to get support for parenting and the disability system. We in Minnesota have been fortunate that in the past we have had two excellent programs providing support for parents with disabilities one through one of our larger counties and one through a nonprofit organization. And these really were national models of trying new ways to support parents. And these were parents with intellectual and developmental disabilities. The sad thing is that with budget cuts both of these programs have been cut. I think you know within the last five years. Right now in Minnesota. No we do not have any formal programs. There's only about and I'm not sure the number right now with the budget cuts that have been happening across the country. But I think there's only about 30 programs throughout the country that actually provide supports and training for parents with disabilities. So most parents with disabilities have very little access to these things. We're talking about such as in-home parenting instruction in less. They have been involved in the child welfare system. Some of your previous work had looked at the prevalence of people with disabilities in the child welfare system. Did you look at the number of children and the number of parent were starting right now to try to find the prevalence of parents with child welfare parents involved in child welfare. We really don't have any idea how many there are.

[00:16:46] There have been no studies done anywhere looking at the prevalence of parents with disabilities involved in child welfare. The number that gets thrown around is of parents with. This is the number that's thrown around. Of parents with Intellectual and Developmental Disabilities 40 to 60 percent lose their child. But that's just really gross estimate. And so what we're in the process of doing right now or actually this is our summer project. Tracy Laverty and I are doing is we're going to be trying to match. So the problem is that the child welfare system doesn't track parents with disability. Records of the parental disability because they're focusing on the child when they actually have done a pretty poor job of recording children's disability even. But parents disability is even further off. And so what we're planning on doing is looking at. We've got this pretty neat data set here in Minnesota where we are able to match data from the child welfare system the Developmental Disability Education and many other systems. And we're going to look at parents involved in the child welfare system who's had termination of parental rights and then we're going to match the parent with the education data to find out if they were identified as having a disability and education data. So that's her strategy for trying to figure out which of these parents actually have a disability. We'll look at the parent and see if they were identified in the education data as having a disability. So you're going to have to assume that all of the people are from Minnesota. Yeah well that's our problem. We'll be able to see if they're in Minnesota or not.

[00:18:25] So the people who are in Minnesota whether they have a disability or not would be excluded. Is there a database of people who are involved in the intellectual disability system that you have there. We have that too but that one is a voluntary system. So the numbers would be much lower. So education because education is mandated to identify folks with disabilities. So they will have higher levels. Now their problem is that they tend to over identify people with disabilities and the education system and some people of different groups have been overrepresented as having a disability in the education system so using any of these administrative data sets are not perfect. What we have done in the past is look at prevalence of kids with disabilities in the child welfare system. So up until recently states were not required to track children for stability either. Now that's changing with the recent reauthorization of CAPTA. But up until recently states didn't have to track it. And about half the states tracked whether a kid had a disability or not in the child welfare system and there had only been two studies looking at the prevalence of kids with disabilities and child welfare. One was using the yes which is the large child welfare survey and then there was another one done in Omaha where they were matching hospital records and child welfare records and court records to figure out what the prevalence was but nobody had actually used administrative data before. So we were looking at administrative data to see in the state of Minnesota. How many kids

with disabilities were receiving services. And we are also looking at when kids with disabilities were in the child welfare system.

[00:20:21] How many of them were ending up in out-of-home placements. So we found that of the kids with disabilities in Minnesota who had an instance of substantiated maltreatment 22 percent had some sort of disability label. And then when we looked at kids over 5 because often kids are kids aren't even identified as having a disability until they reach kindergarten or get into the school system that if you looked at kids with disabilities average five substantiated maltreatment twenty eight percent were identified as having a disability. So that's a huge number. You know over a quarter of the kids in child welfare have some sort of disability label. You know there's lots of different reasons why that could be lack of support the parents might be because they have a disability diagnosis. The kids have a disability that the child welfare system thinks they're more at risk than other kids but the risk might not actually be that different than for kids without disability. What was the prevalence of kids who were not returned to the home. That was just in general. And then looking at comparing kids with disabilities and kids without disabilities kids with disabilities were a little more than twice as likely to be placed out of the home than kids without disabilities and the older they get the higher it got. So yes. So there is something going on there which makes us think we really need to look into this more. Are kids with disabilities being supported when they are placed out of the home. Are these foster care homes accessible.

[00:21:57] You know we know that there's treatment foster care for kids with some types of disability but not for other types of disability. There's also the chance that some of the kids who are experiencing maltreatment are then labeled as having a disability so they can get more care. That particular said you were looking at disability generally across the board. Yeah we were looking at disability generally and saying well we're looking at how the child welfare system identified them as having disability. So they have these different disability codes which child welfare worker can enter in as the child having. So it's not surprising that the most prevalent code was emotional disturbance. That's what they called it. But even without that there were lots of other types of disabilities developmental disability was pretty high to about 10 percent of the kids who had a disability had a developmental disability. There was lots of kids listed as having a disability but the disability was known when we're having child welfare workers in or in disability and in most states including Minnesota. There isn't a whole lot of training for child welfare workers and disability. It's not surprising that they might not know this as well as folks in other systems might know. Which is interesting because they're the ones that can provide services when the towns identified. It's difficult when these systems are so big and so siloed that in large systems they might not have the chance to interact like they could. So the child welfare workers have so much that they have to know and so much that they have to do that disability is something that just might not be at the top of their list. And so there is really a need for collaboration. And we've looked into that too.

[00:23:49] In a previous study where we were looking at what actually happens when there is a case involving a kid with a disability in Minnesota is a county based system so every county has a different system of what they do and some counties have dual case managers where they have a case manager in child welfare and a case manager in the stockade developmental disability they'll have a case manager in developmental disabilities too and they work together you know that can work really well. There are a few special units where I know there's some of these and other states as well within the child welfare system where there are disability experts within child welfare. I think this is a great model us. You know if there's a kid with a family that has a kid with a disability it will go to this either particular unit. Focus is on disability or this particular worker within the unit that has expertise and that can work really well. Did you have a chance to look at how that affects children being taken away. Yeah no we haven't done that but that's certainly something that we would want to look at. And we actually need to the next step is to look more broadly and see how these different models are being implemented because child welfare is not a federal federally run

program. Right now they have federal money available. And each state runs it differently the state runs it. And some states run it as a statewide system with regional offices. Others have county based systems like Minnesota and to look and see how it's done in different places.

[00:25:28] It's something we have to do before we then figure out how are we going to see what works best. We did find you know in this county based system we've got some pretty small counties in Minnesota and well we don't know what the actual outcomes are. We did see the interaction really worked well where the developmental disability worker and the child protection worker pretty much in the same office. They know the same families and they can sort of work together to figure out what kinds of supports we can do and this just really isn't possible when you're working in a huge county where you might not be in the same building. Yeah my experience is they don't necessarily interact that much right. And they know you know it's not their fault they just just isn't set up for interaction. The two systems work usually very separately from each other. You know we might be able to learn something from the smaller counties where they really work as a team and for people who are in her acting with more than one system that can really work well for them. So they're getting some continuity and support but going back prevalence and whatnot is something you've been doing in the past. We just actually finished the prevalence study recently where we're looking at the prevalence of the kids in out-of-home placement and now we're shifting using that same data set to look at the parents with disabilities and try to figure out the prevalence for that. It'll be really exciting because you know we've been throwing out numbers for a long time and we really do not even know what the prevalence is or how many. How many parents were talking about.

[00:27:10] Most of the work for parents with disabilities has really focused on what we can do to change the parents and teach the parents and train the parents. And there's been a big emphasis on what can we do to make parents better parents. And so there's a lot of psychologists cognitive psychologists developmental psychologist trying to figure out what sort of training models work and where Tracy and I are really coming from as you know. Yes everyone everyone can learn to be a better parent. I can too. We're focusing more on what are the supports that we can give to parents and what can we which really comes from a social work perspective. You know looking at the broader environment and what are the laws that are affecting parents with disabilities what are the supports. How are we. How are we. Including parenting as a regular part of life for people. And that's something that all parents with disabilities will be good parents or should be parents but to but not to just assume that parents with disabilities can't parent their kids. Now in going about doing your summer project have you partnered with the Education Department to get that information. We have a program in Minnesota called min link which is a number of different agreements with state departments. So the Department of Education Department of Human Services. And so we actually have all of this data in-house here. So it's a great resource so we have a number of doctoral students doing their dissertations. We have faculty looking at different projects and you know it's not just child welfare it's housed here in the child welfare center.

[00:28:54] But there's education data that folks from Education College of Education can use. There's income data so it's a really great resource for doing research using administrative data. Noting the limitations of administrative data so we can know what's in the system but it's not to say who was doing a national random randomized sample for instance child welfare workers may or may not decide to put down that the child has a disability so you might actually have more people in the system than this actually listed. There's arguments that we're both either overestimating or underestimating the numbers. We're really not sure about that right now. We do know that if we look at the estimated prevalence rate of disability or the census data prevalence of disability in Minnesota that we have way more kids with a disability and the child welfare system and we should have if we're looking at the overall prevalence because of who's labeling it. We don't know if these kids are the same kids or not. So the census data has a lower prevalence of people with disabilities generally speaking. Right. So we could say from that that kids with disabilities are overrepresented

in the welfare system but we're using different measures to measure disability. So we're not exactly sure about that but it seems like that's probably the case certainly in out-of-home placement. We have a lot of kids with disabilities are in out-of-home placement and these kids are harder to find permanent homes for. So these kids with disabilities are more likely to stay in the child welfare system and then transition into adulthood or out of the foster care system as well.

[00:30:34] Does your state provide out-of-home care outside of the child welfare system for families. Yeah we do. But there are options for that. But oftentimes that happens through the child welfare system. But then your most recent is trying to find out what kind of supports that you can give people since we know that states are changing to look at parental support. Now that courts are going to start requiring that that they need information on what these parental supports are. So we're trying to get this information in line for the changing state policies so we can see yes when the court says you need to you need to assess parental support. We have some information on what parental supports are. And so that's what we're doing right now is trying to come up with a baseline of what what are typical parental supports that parents who have disabilities need and want and find useful and then these might be the types of supports that eventually in our dreams new ways are made available to parents with disabilities. So there's different ways of making change. That's not the only way to do it. But our strategy is to do it this way to find the laws are changing and we can provide information on how we can change the laws that fit with best practices and then provide information for the system on what the types of supports are then maybe this will sort of push things along. We'll see. We've been pretty happy since we started doing our policy work looking at the discrimination laws and we actually made a guide for legislative change and we passed that out pretty broadly.

[00:32:13] There's been a number of states that have changed their laws so it's very exciting for us to your whole face maybe that Soto will change federal law. Minnesota of course coming from Minnesota is already ahead of the game. So we never had parental disability in our state law. That doesn't mean that they haven't looked at it. So it's not coming just from Minnesota. Minnesota has had you don't have to have parental disability written into the state statute for the courts to look at parental disability but it certainly makes it easier when you do have it written into. Do you see a need maybe for education for it to the courts as well as a child welfare worker jobs. Absolutely. There are a key player in this which is why we were focusing on the statutes because we think that's important to address if parental supports is written in the statutes and we're hoping that they'll start looking at it. Yes but there's a huge need for education and the courts court system all the way to judges et cetera. And you know that's something that we probably haven't been focusing on enough. You've talked about a little bit but what would you say the implications for social work practice in particular that your research has. I think most directly for the child welfare system and anybody working in the developmental disability or other types with disability services is to look at the concept of two things.

[00:33:34] One is to look at the concept of parents as needing support for parenting just like it's parents with disabilities needing the support for parenting just like other parents need support for parenting and to not try to focus on pushing the independent parenting aspect. And this really fits within the new trends in child welfare. Anyways looking at differential response and all of that but sort of broadening the concept of supports to including the concept of parental supports and recognizing that parents with disabilities with supports can parent their kids. They might not be able to parent their kids by themselves. They might need broader support. And also the parents with disabilities and their families typically know what they need. And so to use them as the expert you know and so we often don't do that for parents with disabilities or parents with general. I think I think there's it's easy to say this and people say this a lot but I think there is a need for collaboration across systems. When we're dealing with people involved in both systems and there's also a need for people to know more about different systems so the folks on child welfare need to understand

disability and the concepts of support and the concepts of inclusion and the social model of disability would really be great for them when they're working with folks with disabilities. And likewise for folks working in the disability service system to understand the child welfare system and understand that it's a completely different system that has timetables and is a voluntary system and to understand what happens in the child welfare system certainly a lot of people involved in these systems do know this. There's plenty of people who go back and forth and really good at collaborating but there might be need to be more formal ways to collaborate or with some set up in a way to allow for collaboration.

[00:35:40] Well it certainly sounds like you had a lot of research areas that you can go with this topic. Yeah it only scratched the surface really. It's pretty wide open. There are really only a handful of people across the world looking into this right now. And Tracy and I know most of them there's a new organization called the Association for successful parenting tasks that just formed a year or two ago. And there's the research group and that's and there's a handful of us in Canada and Australia and the United States and folks in England you know and we pretty much all know each other. There's also a small group out of a DD the American Association of Intellectual and Developmental Disabilities that's looking at parents with disabilities. But as far as we know there's most of them are psychologists there's not very many people looking more broadly at that sort of exciting. But it also feels like all we need to keep going and all sorts of different directions at once because there's so much so much that's needed. It sounds like good research that definitely needs to be done. Is there anything else that you want to say that we haven't already covered. I don't really think so. I think the main point is that there are kids and parents with disabilities who interact with the child welfare system and we don't know a whole lot about how they're faring. We don't even know about how many in some cases how many of them there are. But it really can greatly affect their lives were involved in the child welfare system and many people need support.

[00:37:15] So our goal is try and trying to figure out what supports people need to be able to you know live a good life. So that's that's our research area. Well thank you very much. I certainly haven't joined the conversation and I hope our listeners do too. Thank you. Enjoyed it as well. All right thank you. You've been listening to Dr. Elizabeth Lightfoot associate professor and Ph.D. program director at the University of Minnesota School of Social Work discuss her work on the intersection between child welfare services and children with disabilities. Thanks for listening. And join us again next time for more lectures and conversations on social work practice and research. Hi I'm Nancy Smith 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 you do we invite you to visit our Web site at www.socialwork.buffalo.edu. Here at UB we are living proof that social work makes a difference of people's lives.