Episode 221 – Dr. Jennifer Cullen and Dr. Jolynn Haney: Understanding and Treating Autism in Women: Using Lived Experiences to Shape Practice

[00:00:08] Welcome to inSocialWork. 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 inSocialWork is to engage practitioners and researchers in lifelong learning and promote research to practice and practice to research. We educate. We connect. We care. We're inSocialWork.

[00:00:37] Hello. With this episode we are celebrating nine years of in social work. The University at Buffalo School Social Work would like to thank all of you for listening to our podcast series. We truly appreciate your support. I'm Louanne Bakk your host for the episode in this podcast Dr. Jennifer Cullen and Dr. Joanne Haney discuss gender differences in the diagnosis and treatment of autism spectrum disorder and the reasons why. Obtaining an accurate diagnosis may be extremely difficult for females. Autism is more likely to be unrecognized or misdiagnosed than women which limits our ability to effectively identify and treat the disorder. Doctors Cullen and Haney describe their current research which involves the socialization process of women diagnosed with autism spectrum disorder within an online community. They highlight the myths associated with females in regards to autism and the strength portrayed by women receiving this diagnosis. Also in this podcast Dr. Cullen and Dr. Haney describe practice implications in how social workers can more effectively work with females with autism. They conclude by discussing resources that are available to help social workers understand autism among women. Dr. Jennifer Cullen is currently an assistant professor at Widener University. Her current research involves Autism Spectrum Disorder among young adults in the role of supportive services. Dr. Jolynn Haney has worked in behavioral health for over 30 years providing clinical and managerial services to support individuals with substance abuse issues serious mental illness intellectual disability. Dr Haney's interests include the effects that diagnostic labels have on identity with an emphasis on autism and intellectual disability. Doctors Cullen and Haney were interviewed in May 2017 by Gretchen Bennett a Speech Language Pathologist and Clinical Associate Professor at the University of Buffalo in the Department of Communication Disorders and Sciences.

[00:03:12] Hello my name is Gretchen Bennett. I am a speech language pathologist at the University at Buffalo in the Department of communcation disorders and sciences. I am the coordinator for a speech language clinical services at our teaching clinic and today I am here with Dr. Jolynn Haney and Dr. Jennifer Cullen. We are so happy to have you with us today on this podcast. To begin, Jolynn when your research focused on women on the autism spectrum can you tell me a little bit about your research and what made you decide to conduct research on this population.

[00:03:51] Sure and you know again we really thank you for the opportunity to share this research. We conducted a study where we examined the lived experiences of women on the autism spectrum by studying posts made by these women on an online autism community web. And so we examined the posts made over a 12 month period and the period started January 2013 and went through December 2013 and ours was a qualitative study. So our analytic method was to examine the textual data to look for common themes among these women who posted on the online discussion forum. My reasons for being interested in this population initially became interested in studying women on the autism spectrum for personal reasons. My older daughter is on the autism spectrum. It's a little bit of a story but from the time she was a small child she always seemed to experience the world in a much different way than other children and she was really very unlike her younger sister who I guess you would say would be the more typical child growing up. And so my daughter's differences were never an issue at home but by the time she got to school they became problematic teachers were recording she didn't socialise with other students that they thought her behaviour was odd and I probably should add that she was in school prior to Asperger disorder being added to the DSM. So

Asperger disorder really wasn't even diagnosis when when she had started school. So she muddled through school struggled through school and we supported her the best we could without really knowing why she was different we would say you know she marches to the beat of her own drum and she's a little bit eccentric by the time she was getting to a high school. She really became disorganised with the school work so we decided to have her evaluated and she was diagnosed as having attention deficit disorder not hyperactive but a DD and I later found out that this is a common misdiagnosis given to some females on the autism spectrum. The psychologist who evaluated her recommended a psychiatric consult for the medication but my daughter was adamant that she did not want to take medication. She didn't think she had attention deficit disorder she felt that she could do better in school and you know that she would try harder and when I think back on it now it seems very sad to me that she was willing to try to be something that was not natural for her. Never forget what she said when we were in the psychologists office she said Mom I know I can be different I really don't want to take medication to make a long story short she did keep trying. We kept supporting her through grade school she attended a regular high school and non-traditional high school and then went on to college. But about the time I guess when she was in high school I thought back to a few years earlier one of my good friends who was a child and adolescent therapist had suggested that my daughter fit the profile for Asperger's disorder and that was right about the time that Asperger disorder was added to the DSM. But the idea was that it was a boy's diagnosis. But when my daughter had high school I started thinking about Asperger and realising that things really fell into place when I thought about my daughter in terms of some of the criteria for Asper syndrome Asperger disorder and even though I was a mental health professional I didn't see my daughter as having a mental health problem which I guess probably most parents would not prefer not to see their child is having a mental health problem but we never viewed our daughters having an illness or a disability. So finding out about Asperger disorder did not really change anything about how we interacted with her. It really just gave us new insight about her reactions and ideas on how we could support her and understand her experiences of the world so I know this is a long story but I'll get to the point that I started and then I was beginning my doctoral program and I began thinking about my daughter's experiences and wondering if other females had similar experiences. So I began investigating gender bias in diagnosing Asperger's syndrome and when I researched information about Asperger's syndrome in women I found there was really nothing there. There was really nothing in the literature this is probably around 2008 2009 and so throughout my doctoral program I just kept writing about women on the on the autism spectrum finding out what I could. So I decided that that really was going to be the basis of my research that was going to be my research agenda. And so this study really was the first foray I guess into examining the lived experiences of women on the autism spectrum by conducting the qualitative research that's very impressive and just a wonderful journey that thank you for sharing all of that with us.

[00:08:02] And what a tribute to your daughter for you to do all of this work and how it changed you and your focus right.

[00:08:10] And she's she's really been integral in my research in presentations. She's already presented with both Jen and I. She has recorded videos with me and things like that so she's she's been pretty integral in some of the research. So that was my path to this research I think Jen's path was slightly different so Jen I'll toss it back to you and see how you can answer this.

[00:08:30] This is Jennifer just to sort of corroborate what Jolynn was talking about as we had sort of similar paths. I don't have the personal connection that Dolan has but what I was doing in my career was supporting college students who were at the time diagnosed with Asperger's syndrome. And what I was finding as I'm trying to educate myself on how to support them in college because what we offer them in terms of support services I worked in a disability service program at a university and what we offered were great in terms of academic support you know at that time and testing private rooms for testing those kinds of things but that really wasn't the challenge that my caseload of gentlemen with Asperger's syndrome needed at the time and as I'm educating myself and trying to determine how to best support them in their transition and college everything that I was finding was really about males on the spectrum and what I. Began to understand and sort of. Was curious about was. Hmm it's noticeable that females really aren't represented here. I guess it's a good thing I'm not really working with females right now but I really started to recognise that. So you know and Jolynn and I started to coordinate a lot of our research together with sort of both found that this was definitely a deficit of information that. There were females out there it wasn't that they didn't exist. There were females out there with either Asperger's or autism spectrum disorders but we didn't we weren't seeing enough information to really tell us what their experience was. We just knew that it was different from the experience of males but we didn't know what their experience was and so that really I think was a great connection for Jolynn and I to be able to say well this is a space where we really want to add to some knowledge around what that experience is like because it is so uniquely different and the services that are available are so limited.

[00:10:30] Yes exactly. What a wonderful collaboration for the two of you to have together. Now a few years ago there were some major changes made to the diagnostic criteria used to diagnose autism. What impact do you think these changes have had on females who are seeking a diagnosis. And I'll direct that question to Jen.

[00:10:51] So the DSM 5 which is the Diagnostic and Statistical Manual that is used to diagnose mental health disorders had a reinvention in 2013. So the DSM 5 which is the book now that's being used to diagnose these individuals saw some major changes to autism spectrum disorders. In fact what we found was that from the four version to the five version we lost a few diagnoses so Asperger's disorder and pervasive developmental disorder and OS not otherwise specified was condensed and collapsed into an umbrella spectrum which was called the autism spectrum disorder. And so that the time that was quite controversial because many individuals with Asperger's for example definitely had a sense of identity surrounding their identification as Asperger's in fact they call themselves Espy's and had a lot of actual pride and identity around that so that was quite controversial to sort of take that out of the DSM and and now just have subsumed by autism spectrum disorders. And. What. That meant was that well we started to see was that there was you know. And we don't necessarily know that was a causative impact but there's definitely been increases in the number of individuals diagnosed with autism spectrum disorder. And the criteria really hasn't changed that significantly. There's still the domains of criteria we have two domains in the DSM 5. Now there's a social impairment domain which has to do with the way an individual interacts socially and the way they communicate socially. And that's kind of the social domain and then there is the behaviour and interest domain which is there's repetitive interests or repetitive and restrictive behaviours part of their interactive piece so those are the two domains that are really used to diagnose an individual with autism spectrum disorders but that really hasn't changed much for females because even though the purpose and the idea of the DSM 5 was to add more information about the impact or of things like race ethnicity and gender on the diagnostic criteria. What those different diagnoses look like among those individuals it really didn't change much about what we know about females with autism spectrum disorders and the only thing that's really mentioned about in the DSM 5 is sort of this comparison that. Girls. So what it says is and I quote girls without accompanying intellectual impairment or language delays may go unrecognized perhaps because of the subtler manifestations of social and communication difficulties. That's about all it says about being female with autism. So what that implies is that. What we know about individuals who are females with autism is primarily based on females who also have an accompanying intellectual disability. But what we know about individuals without an intellectual disability and who are female continues to be very limited and we really don't understand what that phenotype looks like.

[00:14:06] That leads me very nicely into my next question for Jolynn why don't we know more about the women who are on the autism spectrum.

[00:14:14] But I think as Jen just mentioned it's not until the DSM 5 was published in 2013 that there was any even any acknowledgement that females might go unrecognized and just as I mentioned my daughter flew under the radar for so many years her differences weren't really named until she was an adult. That's a common theme among women on the spectrum that they're able to successfully mimic acceptable social behaviors so that their differences don't seem too far off from the norm. And then in addition the diagnostic criteria has been developed based on the male expression of autism. So you know males exhibit the types of behavioral problems that bring them to the attention of their parents teachers et cetera. And there were researchers in 2003 Thompson Caruso and Ellerbeck published an article where they noted that females tend to internalize problems whereas males tend to externalize problems and they concluded that the diagnostic criteria will be biased towards the gender that externalize the psychic distress and exhibit socially unacceptable behavior. So in other words if you're not doing something right and you're acting out that's going to come to the attention of people and that's what the diagnostic criteria are going to be based on and you can also see a parallel with this with attention deficit disorder as well. When I first started researching this area I couldn't find too much on gender bias and autism. So I looked to the attention deficit disorder research and found that there had been quite a few studies that talked about the same phenomenon occurring with girls being diagnosed with attention deficit disorder at a much lower rate than boys because they tended to have attention deficit disorder. And boys had the hyperactivity version of that attention deficit hyperactivity disorder. And even if we look back to Hans Asperger's original cases these were all boys who were referred to his clinic after they exhibited overtly aggressive behaviors or they were oppositional to authority or they weren't behaving in school. And so it's also notable I think as Jen noted in the past females who were diagnosed with autism were those who had intellectual disability and probably as a result had corresponding overt. Behavior problems or issues. Another issue though is that for the most part the research that's been conducted on autism has been quantitative and the few qualitative studies that have been conducted have not been conducted with individuals on the spectrum as the primary informants and this whole culture really for both males and females that researchers tend to look to teachers parents and siblings for information about their autistic students child or simply the very few studies have asked the person on the spectrum about their lived experiences.

[00:16:42] That's what I really like about your study when I was reading through it and you're really capturing what is actually being experienced for those individuals. Now for your study you were looking at individuals online. Jen what did you think the benefits of doing this online were. And did you have any disadvantages.

[00:17:03] So I think. One of the actually probably two of the main advantages to studying the population online and I think what you maybe are starting to glean from this is that there aren't a lot. Of Females that we can access that we know about who have. Been diagnosed with autism spectrum disorders. So being able to access this population online meant that we had access to greater numbers of individuals and females who identified with having that diagnosis. So by being able to access greater numbers of females we were then able to really begin to understand more about the socialization of these individuals and to be able to see that socialization happen in an online format that was very authentic and organic that was not a therapeutic setting was not a setting that was. Sort of created as a social skills group or a therapeutic process but it was an organic mechanism for females with autism spectrum disorders to be able to socialize and interact with each other. So that was a definite advantage to using the online format that gave us an insight to the lived experiences of these individuals. One of the limitations though right one of the disadvantages to this mechanism for accessing the population is that it's still in a way restricts the population because we're only able to see the pattern for females who want to socialize. Right. So if there are female to identify with autism spectrum disorder that really don't have an interest in socializing and don't want to engage in an online community. We're still not quite accessing their experience of being female identified with autism spectrum disorders but it's at least a start. It's a glimpse into a mechanism for females to be able to find each other and connect.

[00:19:07] And it's wonderful for you to look at that and start that conversation. Now can I ask you a question about the study were the individuals that were part of the study were they aware that it was being monitored.

[00:19:19] The answer is No. This was the secondary data analysis. So we weren't interviewing women live we were just looking at the textual data it was strictly anonymous we didn't accept names and fact online most women have user names and things like that. Another thing that was unique about our study in qualitative research is you may be aware many times direct quotes are published to or printed two or extracted from the data to provide example to different themes that are found and we decided we weren't going to do that because we were concerned that someone could pop directly into a Google search you know and track somebody down that way. So when we received IRB approval to conduct this study we purposely stated that we were not going to include any direct quotes or anything that could directly identify the women that we just really looked at the text itself.

[00:20:05] Right. This is Jen just to sort of expand on that to really we were trying to find sort of general themes general ideas about what individuals had to say about being female with thought this resort are so you know we were very careful of making sure to protect the anonymity and confidentiality of the forum by not putting those types of quotes in because the intention was not to take anything away from. That format as a mechanism for safe socialisation for those individuals but really just to see how is this used. And then what are they saying about this experience that they have and it made it very organic because it was just what they would have shared Cholon. What were some of the concerns that were expressed by the women on the site.

[00:20:54] Well. You know what stood out to me the most was that the women felt misunderstood and isolated and it really is a myth that individuals on the spectrum don't want to have friends or be in relationships. Some of the women felt that others didn't believe they were on the autism spectrum because they didn't fit the stereotype of what others thought autism looked like they were frustrated by other suggesting they were looking for attention by being different or were just being difficult or that they could act normal if they just wanted to and there was also concern about disclosure you know was it a good idea to come out as autistic and what might the positive and negative consequences be for doing so.

[00:21:31] I'll direct this question to Jen. Why is it that these women have difficulty getting an accurate diagnosis.

[00:21:39] Well one of the things that potentially prohibits women from getting the accurate diagnosis is the idea that. Because there's limited research and understanding of what the female phenotype is you have clinicians who aren't necessarily looking for it. So what you have is you have individuals who present diagnosticians with different challenging behaviors or struggles that they're having and then the lens gets focused to different diagnosis that might better explain it because we traditionally don't think of autism spectrum disorder as a female type of disorder. So what happens is you have an individual who's a female who presents to a diagnostician and they have a series of challenges and things that they're seeking services or treatment for. And. The diagnostician look at things like a DD as Jolynn was explaining or anxiety disorders or depressive symptoms and those are the symptoms and then get treated and those symptoms are what are supposed to be the. Cause of the social challenges that are having. So for example if someone presents with anxiety you're not thinking about oh this is a social challenge or a social deficit it's that oh your anxiety is creating the social difficulties that you're having. So if we treat the anxiety or social challenges will go away. And what we know now about autism is that the social challenges are the diagnostic criteria that we're actually looking at. Right. So we have this situation where the. Clinicians don't expect females to have autism. Therefore their predominant lens is to look at the different behaviors that the person is presenting with and then try and treat that way. The other piece of it as Jolynn already mentioned is that. There is what little research we do have indicates that there may be a socialisation that females present with that enable them to mimic. Except the behaviors you know that the example that Jolynn's with her daughter that she didn't want to be on medication so she said I can be different. I can act differently. So the idea that females are somehow able to better mimic socially appropriate behaviors are acceptable behaviors that help them fly under the radar of the diagnosis which then means that these individuals go on diagnosis or are under diagnosis for a significant part of their lives.

[00:24:14] Yes. So for some women they may not have realized that they would have fallen into that diagnosis. I'm sure that there are many different reactions. Jolynn what were some of the reactions that the women had after receiving the autism diagnosis.

[00:24:31] Well. You know for many it was relief they felt relief that they could finally put a name to their difference for others. They talked about getting a diagnosis meant getting their lived experiences validated. For others it meant receiving certain services that they had been seeking some accommodations. And then for others there was concern or even denial they thought they had the diagnosis. But when they finally got it they weren't really ready to accept that yet. They feared how others would perceive them. And then they also had anger at professionals that psychiatrists and doctors who told them there was nothing wrong with them or were diagnosed or medicated them for some other mental health condition. I think that getting a diagnosis can be a double edged sword in some cases because being diagnosed could open the door for access to services and accommodation. However in our medical model focus world diagnosis means pathology and so pathology causing autism is something that autism rights advocates really rail against that neurodiversity doesn't equate to psychopathology. As I mentioned we never thought of our daughters having a mental health problem or having deficits. We treated her the same as her neurotypical sister. We had the same expectations and everything that went along with growing up raising a daughter and we didn't care if she does things her own way as long as she did things and one of the things I wanted to add to Jen's comment is one of the ways that the women found some of the older women found out they were diagnosed with autism was through their child. Their child was diagnosed with autism and they found out that way by going through that process with their child they will to identify that they were on the spectrum and help them identify and understand themselves more for the online community groups.

[00:26:04] What's the socialization process like for women who engage in an online community for a persons on the spectrum?

[00:26:12] So this is Jen one of the things that we found when we were looking at this online community was that this really became a space for the women to be able to find a place of acceptance and belonging and that there were a lot of connections and friendships being made in this online format that. Not only help them find a space where it's a community that they were coming together. They were forming intimate relationships. They were sharing problems they were finding validation of their experience and their symptoms. And so this became a very legitimizing experience for many of them because it enabled them to not feel alone feel like their experience their. Experience of their symptoms their experience of the diagnostic process. There were similarities and there were other people and they were able to share their frustrations their frustrations with the system their frustrations with the expectation that they were somehow supposed to try to fit in with everyone else. And this became a place of acceptance. And a lot of self acceptance that happened in that Almight forum. So the socialization piece was more than just finding friends and making connections but also finding themselves and experiencing themselves in a community in a new way that many of them shared was with some that they hadn't had before.

[00:27:44] Very nice. Jolynn what myths were dispelled and what strength did you find or were discovered through this wonderful research.

[00:27:53] Well you know the primary myth that our data dispels is that women cannot have autism or be autistic. And it's also clear from the population we studied. Which I think was just over 200 unique women that some females on the spectrum do one friendships they do one intimate relationships many are in intimate relationships and they do want to be connected to others. I think it dispels the myth that people on this spectrum are not capable of empathy. And it also brings to light that their expression of their inner world their empathy their thoughts their feelings may not be recognized due to the neurotypical standards that have been set for socialization and emotional expression. There is a popular theory that the extreme male brain theory. I think that the extreme male brain theory of autism is very harmful and hurtful to women on the spectrum because it pigeonholed them into this certain type of behavior it denies them their womanhood. And it assigns them a male centric label for their difference. One of the strengths we've discovered is the resiliency of these women. They were resilient to adapt to their world to be persistent in the search for answers about their differences and to seek a diagnosis and accommodations. And these are not women who are being victimized by an autism diagnosis but they're women who were taking ownership of the autism label and searching for connections with others who have similar experiences. No chance. How can practitioners researchers or policymakers better understand these issues that these women are facing. I think the first thing that practitioners researchers and policymakers really need to understand is that the experience of many females is that they are either undiagnosed or mis diagnosed and that that's really the first thing that we need to understand right is that when we are working with these individuals that their reality of their diagnosis may not have happened for them and that they need to. Advocate for them to have an accurate diagnosis. And. That being part of that then is to. As practitioners help these individuals seek services that they need for the issues and the challenges they have. So we have this sort of these two groups we have a group of females who may not be diagnosed accurately and as practitioners and policymakers we need to advocate that the diagnostic process include them to get better diagnostic procedures. Then we have this other piece where we have individuals that and many of these individuals on the. On. In this research indicated that even though they have autism or have gotten the diagnosis of autism doesn't mean that they're not potentially going to seek services for other disorders it's. It's quite common for there to be a comorbid diagnosis. They also have a spectrum disorder and anxiety or autism spectrum disorders and depression and that some of these individuals may seek the services not for their autism but for their depression or their anxiety and that as clinicians we need to meet these women where they are when they present for services and rather than looking at the diagnosis of autism and say oh we are going to help you with your socialization skills maybe that's not what they really want to do maybe they want to work on their depression and maybe they want to work on their anxiety and so it's very important for us to approach individuals from a person centered stance where we're meeting them where they are. We're seeking to understand their experience and understand what it is they're really looking for in terms of the treatment process and then that will enable us to to create services that create treatment planning to identify what we want to work on from their perspective because they're going to be setting the goals for us as opposed to us as diagnosticians practitioners policymakers setting the goals for them.

[00:31:45] Yes I always think it's so important that we make sure we're listening to the client so we're looking at it from their point of view. Was there anything you discovered that surprised you and how direct that to both of you I'd be interested in hearing.

[00:31:59] This is Jolynn. I will say I was a bit is that the women were as candid as they were online. It was eye opening to me to find out how engaged some of the women could be in an online community and really how hungry they were for knowledge about autism and how important it was for them to feel their stresses were valid. I just was really amazed at the depth of information that they that they provided. And then I was also surprised at how much the women's experiences really resonated with me in terms of my own daughter's experiences. And it really gave me personally a different perspective on my daughter and a greater appreciation for her experiences and a richer appreciation for the experiences of women on the spectrum.

[00:32:39] This is Jen so one of the things that surprised me about this research was the. I really didn't realize that the diagnostic process was such an obstacle for many of these individuals so that was really surprising to me to know that many of these women were trying for years to obtain a diagnosis that fit what was. Their experience. So that was a big surprise for me. The other thing though that I found was that they used the online forum in a way that was more than just seeking information and getting information. So my experience of the Internet and the way I use it is that I go in because I want to look and find some information and I get that information. And now I have more knowledge. And so I guess maybe that was my underlying assumption that that an online forum would be a place where people were just to get a knowledge seeking type of experience. But there was. A lot more emotion in that online community than I was expecting and it really became in the true sense of the word a community where there was belonging and friendship and self-esteem building and attachment in ways that I had not ever really seen in an online forum before.

[00:33:53] You know this is Jolynn again there was we noticed that when someone new would joined the forum a new new woman would join the forum there was one individual in particular another female who would reach out to them immediately and offer them all of the resources that she had on women on the spectrum blog websites and everything. So it was almost as mothering kind of mother kind of thing

[00:34:14] That's so wonderful to be and it sounds like it was such a supportive helpful group for all of these women and for you to be able to look at it and see how it could help others. What can service professionals learn from your research and why specifically should social workers develop a better understanding of this population. And I'll direct that question to Jen.

[00:34:41] So the first saying is. That females who present to us. May be undiagnosed or underdiagnosed. And so that's the first thing that we need to be aware of is that the diagnostic process may have been a struggle for these females and we as advocate and social workers need to understand that their experience may be that they're they're not working with the accurate diagnosis. The second thing though is that. As social workers and advocates we need to understand that when we're working with a female who does identify as. Having autism spectrum disorders that they may not. Be. Experiencing the socialization challenges as a problem. And so we need to work with them with the issues that they present to us. So if they want to work on anxiety that's what we work on. So as social workers we need to always remember to be person centered and to work on the goals and objectives that our clients present to us regardless of the diagnosis that we understand that they may or may not have. And then the third thing which for me as a clinician was so important was to realize that. I need to think about socialization when I have an individual who presents with wanting to increase their socialization that I need to think outside of the box of the neurotypical socialization process and that for someone who does have a diagnosis of autism the socialization process may be uncomfortable. So maybe trying to think outside the box and be creative by using an online forum where the subtle nuances of the nonverbal communication style that can sometimes be a challenge is taken out of the picture. And so that enables for a more organic and authentic type of socialization to happen that is more comfortable for some individuals with autism. So I'm trying to be creative, we're looking for mechanisms to help support these individuals who truly want to expand their socialization but do it in a way that's comfortable for them and present with the diversity that they're presenting with.

[00:36:58] Jolynn, Can you tell me a little bit about the practical implications of their research or practice policy social work education or future research.

[00:37:08] I think the implications really are that clearly social work education needs to do a better job of including more and more accurate information about autism spectrum disorders for males and females but including subtopics. Such as race. So in addition to diagnostic disparities in gender there are also racial disparities in diagnosis. Also the research should include persons on the spectrum and use inclusive research methods for example participatory action research and to move from deficit based disability medical model research to a more strength based type of research. We need to have better awareness in the social or community about identity first language that some persons on the spectrum want to be referred to as being autistic rather than having autism so you know in the social work field and the human service professions field we're taught to use Herson first language it's not a person who's autistic a person who has autism but many people who are on the spectrum don't want to be considered as having autism because they feel autistic is something. They are it's not something they have. I think as more and more women are identified with autism there will hopefully be a shift away from our male centric view of autism.

[00:38:21] Jen and Jolynn thank you for sharing all this wonderful information about your research and your study and what you've learned about the women that you were able to learn from. Where do you see your research going in the next five to 10 years.

[00:38:38] So this is Jen. The first thing that I'm hopeful for is that we'll continue to research in a way that helps us develop a deeper understanding of the experience of being female with autism and how that presents itself and in particular how that then impacts their life transition and what their life is like as they move from just different stages of their life learning about themselves and learning about the diagnosis. And then you know as an ancillary to that hoping that that research will continue to explore alternative mechanisms for socialization rate helping to figure out ways to increase socialization for those individuals who want to do so in a way that is less centered on neurotypical mechanisms for socialization.

[00:39:34] And this is Jolynn. I see the research being geared more towards acceptance other than cure that autism may not necessarily be something that we need to apologize and sticks but rather except in accommodate and appreciate the differences. I also expect and this is just in general not specifically to women but that research in the future will be more nuanced because we know that autism is a very broad spectrum. And I think the current research tends to focus on people who are at the extreme ends either end of the autism spectrum but we really don't know a lot about all the different variations that occur along the spectrum. So I would think and I would hope that research would move towards looking at some of the different variations among individuals on the autism spectrum.

[00:40:19] Now I'm sure people will be very interested to know what resources are available for women on the spectrum and for social workers who are interested in really getting to know more information about this population.

[00:40:32] This is Jolynn and I'll respond to that first. You know every day I search the internet. Search every day but every time I search which is quite frequently it amazes me how much information is coming out about women on the autism spectrum. When I compare to my searches back in 2008 2009 when there was virtually nothing. There's just so much more now. Jen and I discovered this wonderful British documentary called autism in pink and you know a lot of the things that the women talk about in this documentary really relate to the themes that we found in our study. There's also a TED talk by a young woman named Rosie King and she talks about how autism freed her to be herself. There were any number of autobiographies and memoirs that have been written by women on the autism spectrum really all one needs to do is search the internet to find information. And there are more and more professionals who are becoming interested in the population and writing about the population and not necessarily publishing in journals but publishing books about their clinical experiences. So those are worthwhile checking and you can do a search on amazon to find things that have been written by clinicians about working with women on the spectrum. There were a couple websites that are specifically geared towards women on the spectrum. There's one called autism in women matters. Again this is another British resource we found that England seems to be more visible in developing and promoting these resources for women on the spectrum. The reason for that I'm not sure but a lot of these resources are based in England and then there's also another website called The Autism Women's Network A.W.. And and and they offer a welcome packet for newly diagnosed women. And then of course there's the online community such as the one we study there are any number of online communities for people on the spectrum and there are a few of these that are devoted to women on the spectrum.I found some research and support services out of Australia to be very helpful.

[00:42:18] Yes yes. So this is Jen and I'm going to talk for a minute about the types of ways that social workers can access information to become more knowledgeable. And our primary source for that is social workers especially licensed social workers are continuing education events to get CEU credit and there one I was doing some research what I found that there are a number and each time there is a real accreditation process and a relicensing process. There are more and more CEU events that are being produced to help us understand the connection between autism and social work and understanding that we as clinicians are engaging more and more with individuals who have that diagnosis. So looking for those types of events in your area is going to be a primary source of education around how to work with individuals with autism in addition to sort of parallel the process of finding out more for women with autism spectrum disorders. Looking at websites websites and the Internet are actually a really good source of information for not only research articles and information that's being put out there in terms of research about females with autism spectrum disorders but also there are Web sites that are geared specifically for advocacy groups and autism websites that have information about what it's like to be with the disorder what it's like to live with the disorder and the challenges that these individuals have and really as social workers that were working from our value base of self-determination and empowerment the more we know and understand about the population the better we're going to be able to serve them and help them create treatment programs that will meet their needs as they're defining them.

[00:44:09] Will the work you both have done is very valuable and so happy to hear about it as I'm sure our listeners are Jen and Jolynn thank you so much for being with us today and being so helpful in this journey to help more women who are diagnosed with autism. Thank you so much.

[00:44:28] Thank you. We really appreciate the opportunity to share our research. Thank you for giving us the chance to get this information out there.

[00:44:37] You've been listening to Dr. Jennifer Cullen and Dr. Jolynn Haney's discussion on autism spectrum disorder among women. I'm Louanne Bakk. Please join us again at inSocialWork.

[00:44:59] Hi I'm Nancy Smyth Professor and Dean of the University of Buffalo School of Social Work. Thanks for listening to our podcast. We look forward to your continued support of the series. For more information about who we are as a school our history or online and on the ground degree and continuing education programs we invite you to visit our website at www.SocialWork.buffalo.edu. And while you're there check out our technology and social work research center you'll find that under the Community Resources menu.