ENDING VIOLENCE
Association of BC

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COUNSELLING WOMEN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

By Dr. Margret Newbury Jones, SHADE Consulting and Counselling

We see all kinds of folks in the work we do as counsellors, psychologists, advocates and supporters. The common factor running through all of them is exposure to sexual violence, abuse or other traumatic experiences. They come to us limping, cracked and broken; sometimes it feels like irreparably so. The folks who walk through our doors come from all walks of life and across all levels of ability and functioning. None of them choose to be in need of our services. Those folks who come through our doors who are able to engage fully in "talk therapy" are the clients we understand and feel comfortable in our skill set to provide competent services to. What happens when the person walking, limping, or rolling through your therapy door isn't one of those? What if they have limited speech, speak another language, or have limited insight into what happened to them? Can someone with an intellectual or developmental disorder (IDD) even successfully engage in therapy (McInnis, 2016)? What is appropriate for therapy with a client who either openly presents with an intellectual or developmental disability, other diagnosis, or about whom you are curious yet have little or no information?

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Folks with IDD, including those with ASD and/or FASD experience sexual violence, other kinds of abuse, and traumatic experiences at rates higher than the general population, although those rates aren't agreed upon nor clear (Baladerian, Coleman, & Stream, 2013; Mevissen & deJongh, 2010). Unfortunately, this abuse, violence, and trauma is often not acknowledged, recognized or treated. Many folks don't report because they don't believe anything will happen, they were afraid or threatened, or they don't know how or where to report. Sadly, in most instances, victims were correct, nothing happened. The vast majority of folks also don't get treatment despite the fact that those who do get treatment report it to be effective (Baladerian et al., 2013).

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Message from the Executive Director

Welcome to the Spring 2019 edition of the newsletter! It seems not so long ago many of us were together at last year's Annual Training Forum, but plans are already well underway for the next one!

We are very grateful to Dr. Margaret Newbury Jones of Shade Consulting and Counselling in Kelowna for contributing our feature article, *Counselling Women with Intellectual and Developmental Disabilities.* Margaret delivered a workshop on this at the last ATF that resonated so strongly with participants and was so well received, that we asked her to write this article to share with a larger audience of our members, which she generously agreed to do. Thank you, Margaret!

I think you will also be interested in highlights from one of the latest Information Bulletins from the Community Coordination for Women's Safety team: *The Importance of Coordination Initiatives as Foundations for Collaboration to Address Gender-Based Violence*. It offers, among a number of things, background about the importance of coordination, the three levels of coordination and CCWS' role.

And please check out news items from members around the province that includes recognition of 35 years of service by the Kamloops Sexual Assault Counselling Centre, Theresa Swan's provincial sexual consent education campaign out of Salmo, and the expressive arts therapy program at the Golden Family Center.

Don't forget to save the dates for the next Annual Training Forum, which will be held on November 28th and 29th, 2019 at the Sheraton Airport Hotel in Richmond. This year's focus will highlight gender-based violence across the lifespan. Until then, wishing everyone a safe and enjoyable summer!

With respect,
Tracy Porteous

COUNSELLING WOMEN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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A client has come to you and whether you know in advance that they have an IDD, they present as someone who is struggling, and you are compassionately curious. What do you do next? The first step feels and looks a lot like what you do with any client: develop rapport. Sometimes these clients will engage with you quickly and rapport will be easy. Sometimes too easy… some won't have had an opportunity to talk with someone about what happened to them and some have poor experiences of appropriate boundaries. Sadly, the therapeutic space may be the only "social" opportunity some of these folks may get; it's understandable they may misconstrue you as a friend versus a professional helper. Gently establish and re-establish your boundaries as needed. Just like other clients, some may take a while to warm up and trust you. One of the ways to work on this trust is to establish parameters around confidentiality; folks with IDD won't assume their information and your sessions are confidential. They will expect that you share everything with their supporters whether they ask you to or not. Being very frank about confidentiality and the limits of it is a paramount feature of your rapport building with these clients.

How *does* confidentiality work when your client has caregivers, family and support people heavily involved AND you worry your client might need some help with generalizing what you're working on for it to be effective? Some clients may invite a support person to join their sessions. This is fine if your client is the one doing the inviting, and it's the same person at every session and not a rotation of staff. When your clients don't invite their support in, it is appropriate to say to your client, "What did we talk about today that you'll need some help with or that your supporter may need to know about? Can we invite your supporter to come and join us for the last ten or fifteen minutes so that you/we can fill them in?" Or, "Can we send an email together or make a call together?" This has a twofold advantage: your client sees you walking your talk about confidentiality and respecting theirs, and your work with that client is much more likely to be successful if they have consistent support. When you are required to report to or collaborate with an outside professional or third-party payer, make sure a release of information is signed by, and explained to your client in simple language so that they understand the need for collaboration and sharing of their information. Letting them know that you are going to contact that outside person before you do so is always appreciated so that a client isn't blindsided if another professional knows about their counselling session before the client shares it.

Like many folks, those with differing abilities such as IDD, may not have a complete referral form outlining their diagnoses. This may be because they don't have a diagnosis, or they don't feel that their diagnosis is germane to their referral because they are coming to see you because of their assault, trauma, etc. – not because they have an IDD or other disability. Sometimes folks leave it off their referral out of fear that they won't receive treatment if they state that they have an IDD.

These clients, like many we see, don't usually clearly articulate (or even know) "why" they need, or are seeking out, counselling. They're often referred for one thing and what they need is another. Sometimes someone else has decided that perhaps your client might need some counselling, but the client doesn't know why. This isn't any different than many of the other folks who walk through our doors.

It is important when doing an intake with these clients (and often their supporters) to get as much

information and collateral as possible. Folks with IDD often have large numbers of paid supporters around them and sometimes few natural supports (particularly adult clients). Figuring out their "systems" and supports is important. For instance, does this client ever go anywhere independently or are they out and about in their community? Did this change after their assault/traumatic experience? Why does the client think they are coming to see you (often they've been told or understood something different or think they *must* see you and they have no choice)? What is your client's story? What do they do with their day? What are their strengths? What do they find hard? How are all those supporters and peripheral people actually involved in their lives? Who are their allies in this process (not everyone may be)? The more information you have the better, although, like with all clients, we need to be mindful of not pushing and re-triggering clients.

Traumatic stress is frequently seen in these clients in the form of behavioural "challenges" – that is, distinct changes in behaviour rather than articulating distress or stress. Remember this is not challenging for them, it is survival. Be curious about what is going on for that client, be careful not to inadvertently engage in a process called diagnostic overshadowing, attributing symptoms to one's disability when they are in fact indicative of something else (PTSD, anxiety, etc.) (Reiss, Levitan, & Szyszko, 1982).

Information gathered; client present – now what...?

In sessions with these clients we need to be mindful of many things, here are a few:

① Be concrete – avoid the use of euphemisms, figures of speech or abstractions. Your language should be concrete, not babyish – just concrete.

② Don't treat adult clients like children. Although their emotional functioning may be similar to a child and they may engage well with activities similar to those you might use with children, don't treat them like a child. Adapt child-based activities so that they don't appear to be for children. Adults have many years of experience under their belt; give them credit for this. We all deserve that respect.

③ Be comfortable with the silence, most folks may need more time to process. Wait for them, don't repeat yourself or change your language right away unless it's clear someone didn't hear you or they ask for you to repeat what you said. Every time you re-state what you've asked, most clients will not process it as the same query, but rather will start over again from the beginning…. every… . time…. Clearly at some point you do need to re-state, but always give the silence some time first. You're ready to continue; they're thinking.


Photo by Clay Banks/Unsplash

④ Check for understanding often, not by saying "did you understand that?" Many folks with IDD are rewarded for being compliant and/or don't want you to know if they *don't* understand or they don't want to offend you if they don't agree with you, so they say YES, most of the time. Therefore, checking for understanding can be done by asking a client to tell you back what you just spoke about, what they are going to try/practice, etc. This regular checking-in helps in two ways, it ensures you know your client understands what you're working on and it serves as repetition which is important for this group of clients.

⑤ Use additional resources – While as counsellors we tend to focus on "talk therapy", be prepared with these clients to use additional resources such as pictures, videos, objects, worksheets, etc. A picture of a place, person, etc. can make the process clearer for both of you. While using additional resources is usually necessary, don't assume literacy on the part of your client. Many

may struggle with literacy and comprehension so be certain that a written resource is going to be understood before using one, or read captions or other written parts of a resource to a client. Be mindful of this before assigning homework which requires reading and writing as well. This is where a supporter may be able to work with a client outside session or they may be able to collect some data for you if you'd like to know something specific like tracking nightmares, etc.

⑥ Time – Some folks with IDD have difficulty with the concept of time. They may relate something to you that happened many years ago as something that happened just today or in the recent past. This is where your very careful intake comes into play, understanding someone's past and their story ensures we don't ascribe a lack of understanding of reality to someone who really just has a poor concept of time. Remember that with untreated trauma it often feels like it happened yesterday. Similarly, some clients with IDD may not be able to manage a therapeutic hour, use your extra time to connect with their supports.

⑦ Clients with IDD, similar to other clients, don't always grasp new concepts, get the gist of counselling, or come to healing quickly. Progress can be slow, and it can seem like you're working on the same things for many sessions. You likely are. This is okay; repetition is a vital part of the healing process. If a client has difficulty generalizing concepts outside the counselling space, they may also have difficulty remembering what you've worked on from one session to another. Don't get frustrated; be okay with the slower pace and those silences in the room while you're working together. We all know counselling is hard work for any client and this group of clients is no different.

Clearly this isn't rocket science, it's counselling, what we've trained for and are good at. Choosing to not counsel folks with IDD or other disabilities leaves huge gaps in many communities for those who need this help. The adaptations we need to make for this community of clients isn't that different from those adaptations we make for any of our clients. They're all individuals and we move and sway with their needs all the time. Is it harder? Sometimes, but most of the time it's not. Folks with IDD and other disabilities are sadly victimized and abused at rates higher than the general population. They too need our support and expertise; they too experience traumatic symptoms, anxiety, depression and other challenges; they too can heal with our help.

Margaret Newbury Jones *is a cisgender, heterosexual counsellor and sexuality educator who works almost exclusively with folks with intellectual and developmental disabilities and the people who support them. She is an independent contractor operating SHADE Consulting and Counselling (www.shadeconsulting.ca) based in Kelowna, BC.*

Margaret has a Doctor of Psychology degree as well as graduate certification in complex trauma and child sexual abuse intervention. Prior to becoming a consultant, Margaret worked in the public school system for 15 years. She has 25+ years of experience working in the IDD field as an educator, counsellor, and advocate. She sits on the Board of the Alberta Society for the Promotion of Sexual Health. Her best teacher has always been her sister Susan, who lives with an IDD.

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