

The International Journal for Direct Support Professionals

Healing, Hurt and Wholeness: Why Therapy For People With Intellectual Disabilities?

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"Sometimes it's not about changing the world, it's about changing someone's world." Dave Hingsburger

The majority of the people we support have had complicated and painful relationships with family, staff and the community. These painful experiences impact a person's general wellbeing and health. It can continue throughout the years to cause psychological pain, affect interpersonal relationships, self-esteem, as well as the ability move forward and enjoy life in a meaningful way.

It was once believed that people with intellectual disabilities do not experience emotions in the same way that people in the general population do. All mood and behaviour issues were once attributed to the disability and not considered possible signs of a mental illness. We now know this not to be true. Like anyone else, people with intellectual disabilities can suffer from mental illness. Like anyone else, with the right support for them, they can heal and life can get better.

Choice and voice are two words we have heard and used in many ways for many years now. We consider that, in someone's daily life, it is important for them to be able to choose how their day and life looks, as well as to use their own thoughts, feelings, beliefs, and interests to be able to express their needs. However, the choices can be limited to what have become the typical developmental service models of support.

Part of the model of community living has been that people with intellectual disabilities are immersed in society and fully taking part in it as they choose. So why not therapy options? Some of us may have had our own personal struggles, anxiety, depression, abuse histories, unhappy relationship patterns, and substance use. If we have been brave enough to reach out for help, think of all of our options. We can seek out the type of therapy that will work for us such as short-term cognitive behaviour therapy, long-term psychotherapy, therapy groups, and many more. We are able to make a decision to heal and to decide which intervention we feel best meets our needs. Many

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people with intellectual disabilities do not have access to all these options or even access to therapy at all.

The concepts discussed below originate from our collective learned experience through our educational training and direct work with therapy clients.

What is Therapy?

Therapy is the treatment of emotional problems such as anxiety and depression. People go to therapy when they are experiencing difficulties in their lives and would like to discuss these problems with a professional. Often, a person's life may seem fine. They may have friends and family who care about them, a job they like, etc., etc., but still feel unhappy. Seeking therapy is a good idea for someone in that situation.

Therapies can be an essential part of someone's healing from major mental illnesses as well. Therapy can be a part of a plan for wellness that may include: medications, psychiatric oversight, and treatment approaches at home with a behaviour therapist. When people have a baseline of emotional stability, they can be ready to begin understanding their mental illness, perhaps how it developed, as well as learn strategies to understand themselves, their needs and the healthful expression of how to meet them. A therapist will listen to their clients discuss their problems and help them develop a better understanding of their needs.

There are many different types of therapy to choose from. Ideally, people with intellectual disabilities should be able to choose from as many options as are available to the general public. These options may include:

Cognitive Behavioural Therapy (CBT): A short-term, goal-focused type of therapy that looks at the ways our thoughts, behaviours, and mood all impact each other. CBT seeks to change one's thoughts in order to change one's moods and behaviours. For example, if someone is constantly thinking, "I am worthless," they may not interact with others very often and may feel depressed much of the time. A CBT therapist will help the person find reasons that they are valuable, leading them to interact with others more often and feel less depressed. CBT typically lasts for eight to 16 sessions.

Psychodynamic Therapy: A type of therapy in which a client, with the guidance of the therapist, examines their past and looks at the ways that experiences may be impacting their present. The client processes and heals the past experiences and makes connections between present and past. This therapy is much more client led than CBT. The length of psychodynamic psychotherapy is determined by the goals of the therapy that the client and therapist develop together, and the pace at which the client needs to move at to do the work. One of the benefits of this therapy can be deep-seated change in a person's way of being in the relational and practical world. This can mean potential for healthier relationships and perhaps working towards personal goals like work and education. It can work to mobilize people to live more fully and creatively. This kind of change takes time. It is good to begin by considering a commitment of two years, although the client may choose to complete therapy sooner or continue past that time.

The Creative Arts Therapies: These include music therapy, art therapy, drama therapy, and dance/movement therapy, in which the client expresses themselves through the arts. Sometimes these will be combined with talk therapy, but not always. While arts therapies can

benefit all people, they are particularly well suited for people who may not be as adept at articulating their problems and feelings, such as some people with intellectual disabilities.

Group therapies: All the above modalities are available in group formats and can be quite helpful for people as well. A few points to remember though. The decision to take part in a group therapy may be best made by the client with the primary individual therapist, perhaps after at least a full year of individual work with a therapist. Group work can be sensitive, and it is most useful when people can go into the group with an improved sense of self. When the time is right, it can be a wonderful way to explore what is being learned about in individual therapy through relating to people in a safe and supported therapeutic environment. Small groups between four and six members may be of benefit to the intellectually disabled population to help them be able to follow conversations, and to be able to get the support needed from the group to regulate their emotions.

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Why People Go to Therapy

It is not always easy to know who to recommend for therapy. Luckily, it is very rare for therapy to be harmful to an individual. That said, some people will certainly benefit more than others. If someone you work with is displaying any of the following signs and is interested in therapy, they are likely a good candidate for therapy:

- It seems challenging for the person to speak their mind even when you know that they do not agree with something.
- A person seems to have a very low sense of self-worth.
- They are eager to please everyone, at the cost of their own comfort and, at times, safety.
- They may present as sad, scared and/or angry often.
- You may hear many complaints of physical ailments over time but, when they are checked out by the doctor, there is no known cause for the pain or discomfort. This may include, but is not limited to, digestive complaints, headaches, or skin irritations.
- They seem to hide from social situations and new opportunities.
- They are hurting others in their homes, day options, family, or community.
- They are often emotionally overwhelmed; this could be anger, fear, or sadness.

Each person may react very differently to their struggles. However, we know, when we see these symptoms, that someone needs support.

Trauma

What causes mental illness? No mental health issue occurs due to one reason. There are always many contributing factors including life circumstance, genetics, physical health, etc. However, trauma can be one frequent cause of mental illness, particularly among adults with intellectual disabilities.

Trauma occurs when something very negative happens to a person, e.g., they experience sexual and/or physical abuse that is still impacting them in an emotionally harmful manner well after the event has concluded. Luckily, people with trauma can be helped a great deal by therapy. Some facts about trauma and people with ID:

People with an intellectual disability are 10 times more likely to experience violence than people without a disability and are three times more likely to be victims of physical assault, sexual assault and robbery than people who do not have an intellectual disability. Therefore, they are at very high risk for trauma.

This increased likelihood of victimization occurs for a number of reasons. The easy-going nature that is often encouraged in people in this population makes it easier for others to take advantage of them. Many people with intellectual disabilities have caregivers delivering their basic needs and often need help with personal care tasks, such as bathing. The more people that have intimate access to an individual, the more vulnerable that individual is to abuse. People in this population are not always aware of what abuse is, and what normal behaviour is. They may also not know how to report traumatic events and may not be believed or heard when they do report. We, as a service industry, are working to change this, but please consider that, for all people, recognizing and reporting abuse can be an extraordinary challenge. Consider that perhaps the person who is the abuser may provide primary care and, to some extent, appear to have a good deal of control over getting daily basic needs met.

Trauma can have a wide variety of symptoms. Trauma in one person can look very different from trauma in another even if they have had similar traumatic experiences. Many traumatized people, however, will exhibit at least some of the following symptoms:

- Anxiety and fear
- Guilt or self-blame
- Depression and withdrawing from others
- Numbness
- Anger
- Mood swings
- Denial or disbelief
- Nightmares
- Difficulty concentrating
- Edginess and agitation
- Physical pain and discomfort

Some people have been so traumatized that working on individual therapies may have a re-traumatizing effect – opening up old wounds so to speak. This may be counterproductive to stability and mental health progress. If you are unsure whether to support a person to engage with therapy services, contact the therapist and discuss this with them in a way that does not break confidentiality. They should be able to provide you with some guidance. Sometimes the healing can begin and continues through a lifetime of good therapeutic support that can come from well-trained teams, and good homes or programs.

Being in Care, Control vs. Personal Agency

Sometimes trauma does not come from a single negative experience but from many small negative experiences spread out over time. Imagine living in a group home, then imagine having had a life with caregivers. Someone often with you, guiding you, at times overwhelming you with what they think you should do, say, wear, eat, etc. Imagine the powerlessness that comes when you cannot simply leave – your home, your life and the people in it – with some security that you can make it on your own. You do not get to choose with whom you live, who your caregivers are, and for how long they are a part of your life. Now take that thought and multiply it by about 1000, and that may get you closer to what it is like for the people you support.

Imagine desiring freedom of living but knowing that you need staff there to help with that. It's confusing and frustrating. Many of the people we work with would like to have the jobs, relationships, families, etc. that they witness the general population experiencing, but think that they cannot. They also contend with the stigma of having a disability daily. The constant sense of helplessness can be traumatizing.

Some of the work that can be done in therapy is to help people express the anger and grief that can come with this reality. It takes work often to recognize this as a source of deep feelings and pain but, for the most part, with everyone it is there if they seek to find it. People need the chance to express this, and to find a way they can have personal agency in their life. Finding a path away from being controlled to controlling their lives. To do this without submitting to the will of others or lashing out from a place of pain at their staff, peers and community can be some of the good work done in therapy.

Your Role in Therapy

Direct Support Professionals are an important part of people's lives and can be helpful observers. In a way, the process of therapy can start with you. Here's how:

- You can track and highlight concerns for people's mental health and work on early intervention.
- You can listen and talk with a person when they are having a hard time. If they are not ready yet, let them know regularly that you are there when they are.
- You can start the conversation about getting help from a therapist with a person.
- You can teach them about therapy and some of the possible benefits.
- You can be prepared to offer concrete therapy options for the time when they may say they are ready to take this step. It is a tough decision and one that, when a person is ready to make, we should be ready to practically support. There may be options at local community centers, through family doctors and perhaps where you work. Investigate – you may be surprised what you find.

Myths About Therapy

They will talk about me, I will get in trouble: They may, they may not. Remember this is a person's confidential space to share whatever they need to. They may bring up concerns. The hope in therapy is that, over time, the person in therapy will begin to be able to navigate relational experiences in a healthier way. That includes the one with you. It's a process, and people need to talk about the ups and the downs in their life.

They will talk about family: The same as above applies here. However, it is important to note that when a history of abuse and mistreatment in families exists, many family members may want to keep this quiet. It could be the abuser, but it may also be other victims who are not prepared for information to come out and be dealt with. It is common in many therapies for family members to become nervous. They may not be supportive. It is the decision of the person in treatment to continue or not. If the person is a consenting adult, it is their choice.

This will make people upset and worse: The truth is therapy can open emotions up and people may leave sessions with emotions. Part of the job of the therapist is to ensure a person is regulated when they leave our office. However, someone may continue to process long after the session is finished. Consider these are emotions that were likely not able to be expressed at the time of abuse or mistreatment, and they need to come out for healing. It is a part of the healing process. Make them a cup of tea, arrange something fun to do with them, tell them you are there if they need you. If they are tired, skip the chores or routine and let them sleep, and perhaps give them space. Do not ask them to tell you about what they discussed in therapy. If they are in art therapy, do not ask them to show you the art they produced. They can share any and all of this information if (and only if) they want to.

It is taking too long: Abuse and mistreatment may occur over a long period. Though most people start to feel some relief by about the 10th session, long term healing takes time. Sometimes years. This is not a bad thing. It takes time to grow and learn and the people you work with have an intellectual disability so it will take longer. Breathe, support the person you work with to be patient. It may seem like nothing is changing, but that is likely not the case. Progress is often not seen daily but accumulates and is seen over time. There is no quick fix.

People don't want to do this: Therapy is a personal choice. It needs to be an educated one. Providing education about community or agency services is an important part of the role of a Direct Care Professional. Many people will often say 'no' if they do not truly understand what the option is. Conversely, they may say 'yes' when they do not know what is on offer. Education is crucial. We need to be careful here. The decision to start therapy is where the therapy begins. It is a first step to healing. Our collective experience is that people want this. They are "voting with their feet." Once someone feels safe and has a good relationship with therapist and a routine for therapy, people reliably arrive at the therapy room ready to work. We hear from people how important this is in their life. They tell us things like, they feel more settled, have more energy, are starting to tell people what they need and want, are less anxious, angry and sad, and they feel better physically. People seem to want more of that, we can all understand why.

Partners in Program (that's YOU)

When we consider therapy options for people, we consider building on some of the exceptional and important work that is being done in the group homes and day options. As therapists, we consider that we work in tandem with DSPs – that we are a team. Consider:

A stable home is a part of the ground work of good therapy. Knowing that you will have reliable and familiar staff who “get you” is really important. For some, they have experienced great unreliability in their life. Things as simple as a person knowing that they will have three meals a day, clean clothes, someone to listen to them, someone to help them understand their world and access the world are, as we all know, essential in life.

While therapy can address and support a personal crisis, the best time for a person to be in treatment is during a period of stability, not in a crisis necessarily. If the person is somewhat emotionally regulated, able to manage activities of daily living, and feeling safe in day-to-day life in general, they are more able to focus and be present in treatment. This means that there is space for the work to be done and change to occur.

We need your help. No matter what the ability of the person in service, typically everyone will need some kind of practical help getting to therapy. This could be transit training and budgeting for fares, time management to come to appointments on time, or transportation. Make the therapy a priority. Some therapy would not happen if this help did not exist.

Supportive group homes and day options are a precursor to therapy. They can lay the groundwork and are very important, when done well. They are also a place to go back to when sessions have been emotionally difficult and a person needs comfort.

Shame and Disability Acceptance

We are starting to see some changes in the world around the willingness to accept that, as humans, we can be carrying emotional wounds and great pain associated with this. There are social and media campaigns, organized fundraisers and community gatherings that are helping to address the shame that has come with sharing our mental health struggles with family, friends, and coworkers.

In society, there is a more general openness to work with a therapist to heal. This cultural shift is beginning to come into the world of people with intellectual disabilities. We are seeing therapy being offered in more community agencies than ever before, even some alternative therapy options such as art and music therapy.

Acceptance of being a person with a disability and learning to love one's self can be a challenging journey. This struggle comes with great shame for simply being you. The disability in a person's mind can overshadow what is truly wonderful and exists in a person. This has the potential to contribute to the world around a person. In therapy, we can work deeply around this shame towards healing and a heightened sense of self. DSPs can help by normalizing the therapy process and disability. Teaching those you support about others who have achieved great things and have mental illness and/or disabilities can help reduce shame. These people

include Terry Fox, Franklin Roosevelt, Robin Williams, Stevie Wonder, Jean Chretien, Elton John, and Whoopi Goldberg. With the right support, who knows what our clients can achieve?

Conclusion

Like all people, adults with intellectual disabilities experience trauma, anxiety, and depression. Like all people, they deserve access to treatment and therapy. They deserve to have a choice in the type of therapy they receive. As direct support professionals, you are in a unique position to support them before and during therapy. You can help them heal and improve their lives in a meaningful way.

About the Authors

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