



ETHICAL ISSUES IN COUNSELLING AND PSYCHOTHERAPY WITH PEOPLE WITH INTELLECTUAL DISABILITY

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Abstract

The purpose of this article is to raise awareness of the lack of appropriate counselling and psychotherapy for people with intellectual disability. There has been limited research on the topic due to clinicians' bias, lack of knowledge about disability issues, and the failure of the counselling and psychotherapy profession to train new graduates in their understanding of disability issues as part of cultural competence and diversity. As a result mental health services for this population have been limited to behaviour modification, reflecting the predominance of medical model of disability. In contrast, the less emphasised social model of disability, reflecting the notion that people with intellectual disability are a minority group is discussed. The literature on the benefits of providing counselling and psychotherapy for people with intellectual disability is reviewed. With a case study, I have demonstrated the benefits of using an integrated approach to counselling and psychotherapy with people with intellectual disabilities using a combination of person-centred and behaviour therapies.

Introduction

As a Social Worker with extensive experience in the Disability Sector, Community Mental Health, Child Welfare, and more recently in Trauma Counselling, and as a mother of an early teenage daughter with intellectual disability, I am very aware of the need to provide counselling and psychotherapy for people with intellectual disability (ID) in trauma and loss and grief issues. However, I have only experienced a few counsellors with knowledge of disability and who can provide adequate service for this population. I have become increasingly aware of the difficulty people with intellectual disability face when accessing counselling to help deal with their traumatic issues.

This paper will present two real life stories and a case study of people with ID in need of counselling, and discuss the ethical issues that arise from the stories and study. It will explore what can be done about them, and discuss the way forward for the field. The two case narratives illustrate the problems resulting from the use of inappropriate therapy and the lack of knowledge of ID by the therapist. The case study demonstrates the benefits of using an integrated approach to therapy and supports the need for the counsellor to have knowledge of the issues faced by people with ID.

Narrative 1

I was the co-ordinator of a community organisation that provided in-home support for people with mental health issues and people with disabilities. One of my clients with ID, a 35 years old woman who I will name Sally lived in a group home. She was supported by the organization with meal preparation. A neighbour's son sexually assaulted Sally when she was visiting her aged mother. She was so traumatised by the ordeal that she was afraid to visit her mother, and then got distressed and became aggressive towards staff. The house manager sent Sally to a Counselling Psychologist for therapy. To my disappointment, after the initial assessment the counsellor prescribed strategies for behaviour modification for Sally.

Narrative 2

Another example of the difficulties in accessing counselling for people with intellectual disability occurred with Joe, a 40 years old man with Down syndrome and consequent ID. Joe's aged mother who was his sole carer suffered a 'stroke' and was admitted into a nursing home. Joe went to live with his sister and her family. Sadly he could not cope with the loss of his mother and his home, and took out his frustration on his young nephews. Joe's sister sent him to a counsellor who only gave her strategies to help modify Joe's behaviour. When the counsellor was told that Joe needed loss and grief counselling he said he had no skills in counselling people with intellectual disabilities.

As a counsellor or psychotherapist, what do you think is the problem in each story? Are you able to help Sally or Joe? If so what therapeutic approach and technique would you use? Are there any ethical concerns about the attitudes of the counsellors in the stories? If so why and why not?

Both Sally and Joe experienced some symptoms of depression and anxiety such as anger, fear, sadness, confusion, sleep disturbance, overeating, crying spells, headache, shortness of breath, shaking and vomiting. However the counsellors were only concerned about the clients' aggressive behaviour. This overlooked the cause of their behaviour and thus did not assist Sally to work through her traumatic stress after the rape, and Joe to grieve the loss of his mother.

The Issue of Medical Model Versus Social Model

Conceptualisation and perspectives of intellectual disability

Intellectual Disability (ID) is defined by the American Association on Mental Retardation (AAMR), as a disability that originates before the age of 18 years, and is characterised by significant limitations both in intellectual functioning and adaptive behaviour, as expressed in conceptual, social and practical adaptive skills (Luckasson et al, 2002). This definition reflects the World Health Organisation (WHO) and United Nations recommendation and endorsement of the International Classification of Functioning, Disability and Health (ICF) as a framework for conceptualising disability (AIHW, 2003). It should be noted that the use of the term 'mental retardation' for intellectual disability is inappropriate and reflects the medical model, which will be discussed later on.

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The AAMR classification system uses Intelligent Quotient (IQ) tests to measure intellectual functioning and categorised the scores into levels such as: mild (55-70), moderate (40-55), severe (25-40) and profound (below 25 points). Impaired adaptive behaviour is also classified into levels of mild, moderate, severe and profound. However, adaptive behaviour is difficult to classify so the AAMR manual provided a broad description of skills for each of the four areas of functioning (independent functioning, physical skills, communication skills and social skills) according to age.

There have been two models used to describe intellectual disability: medical or clinical, and social models (WHO, 2002; Cocks, 1998). The perspective of the medical model is that the disability is a condition or disease within the person. In contrast the social model locates the disablement in the environment and in society that fails to appropriately accommodate and include people with disabilities (Olkin, 2002). The medical model has been used to describe people with intellectual disabilities since the 19th century and the emphasis was on curing them. Thus the historical link between health and mental health service, and people with intellectual disabilities that has contributed to thousands of people with intellectual disabilities locked up in large hospital-like institutions in Australia where their social needs were not addressed (Cocks, 1998).

Due to the Rights Movement of the early 1980s, the paradigm shifted from the medical model to the social model whereby people with ID have the right to live in the community, be included and participate in social activities, and have access to information and services like any other minority group (Olkin, 2002).

Review of the literature on the benefits of providing counselling and psychotherapy for people with intellectual disability

As with the general population, people with intellectual disability are referred for and seek out counselling and psychotherapy for various reasons. Some of these reasons are for grief and loss issues, interpersonal traumatic experiences as a result of exposure to the 'freedoms and dangers of society' (Lynch, 2004), issues with transition to community living, and mental health disorders like depression and anxiety. However mental health clinicians by and large continue to neglect this area of practice (Lynch, 2004) as in the past mental health services to this population has been limited to cognitive appraisal and behaviour modification (Baroff, 1986).

There is not much literature on the provision of counselling and psychotherapy to people with an intellectual disability. I conducted a literature search from Medline, CSA Illumina, CINAHL, PsychINFO, and EBSCOhost and found few articles on the topic, but most of which were published in the *American Journal on Mental Retardation*, *Mental Retardation*, *Research in Developmental Studies* and *Journal of Intellectual Disability Research*, and only few in *Psychology* or *Counselling and Psychotherapy* journals.

Although the idea that counselling and psychotherapy can be effective for people with intellectual disability has been increasingly accepted, concerns have been expressed regarding the lack of empirically sound research (Butz, Bowling and Bliss, 2000; and Lynch, 2003). Butz, Bowling and Bliss (2000), asserted that most clinicians avoid addressing the mental health needs of people with ID because of lack of research and clinical study of the topic. Nezu and Nezu (1994 p.34) refer to the available literature

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addressing counselling and psychotherapy with people with ID as “sorely lacking”. A recent study conducted by McCabe, McGilivray and Newton (2006) on a small sample concluded that intervention programs are effective for the treatment of depression among people with ID. Baroff (1986) conducted a research on the topic and found out that both individual and group psychotherapy are undoubtedly therapeutic for people with ID. He asserted that through therapy clients are able to ‘discharge troublesome impulses verbally rather than behaviourally (pp.92-93).

Hurley, Pfadt, Tomasulo and Gardner (1996, p.371) also reviewed the literature on the topic and indicated that “few controlled studies have been performed, but results of those have been positive”. However they pointed out that results were effective because psychotherapy was ‘adapted for each individual’s cognitive level.

A large systematic review of effectiveness studies has recently been conducted by Prout and Nowak-Drabik (2003). These authors looked at 92 studies covering 30 years period (1968-1998) in which researcher examined the effectiveness of psychotherapy with people with ID. They concluded that psychotherapy is moderately effective for people with ID, and yields a moderate amount of change for this population.

The Ethical Issues involved in counselling and Psychotherapy for people with ID ***Reasons for the lack of research and clinical study on the topic***

The main reason for the lack of research on the topic could be due to lack of knowledge about disability issues among clinicians. Olkin (1999) conducted a survey among psychologists in America and discovered that majority are not familiar with the commonalities of the disability experience. Olkin and Pledger 2003, p. 297) argue that psychology has embraced the concepts of cultural competence and diversity, but students in clinical psychology are not being trained to be competent in their understanding of disability issues. These authors’ argument has been echoed by a recent study conducted by the United Kingdom Royal College of Psychiatrists (2004). The College discovered that the barrier to accessing counselling and psychotherapy for people with intellectual disability is lack of appropriate training and supervision of clinicians in disability issues.

A study of a large graduate psychology curriculum in the USA (Bluestone, Stokes and Kuba, 1996 cited by Butz et al 2000), found that disability received the lowest amount of coverage among seven diversity issues. In a similar study Kemp and Mallinckrodt (1996 cited Olkin, 2002 p.132) concluded that most professional programs do not include disability issues in their curricula, and they pointed out that ‘even a small amount of training on issues of disability may be associated with significantly less bias in case conceptualisation and treatment planning.

Olkin (2002) also pointed out that the social model of disability incorporated the ideas of people with ID as a minority group similar to ethnicity or sexual orientation. In a recent discussion paper by William and Heslop (2005), these authors argued that the medical model of disability has predominated in discussions of mental health support for people with ID and that the social model approach could have much to offer. The argument then is why has the counselling and psychotherapy, and psychology professions made

provision for minority groups like ethnicity and sexual orientation in their training programs but have ignore disability?

Does it mean that the profession has neglected its ethical responsibility and legal obligation of service to the people with intellectual disabilities? It should be noted that based on the International Bill of Rights (hrea.org, 2003), the UNO developed the first disability policy on the Rights of Disabled Persons in 1971 - "Declaration on the Rights of Mentally Retarded Persons", then in 1975 the "Declaration on the Rights of Disabled Persons" which stated that "*Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthotic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities, and skills to the maximum and will hasten the processes of their social integration or reintegration*" (Resolution 3447, item no. 6, United Nation Enable, 2004).

Another ethical issue is the term 'mental retardation' use by the AAMR that has a negative connotation to it. After 35 years since the "Declaration on the Rights of Mentally Retarded Persons" was proclaimed the AAMR has finally changed its name. The announcement was made in July 2006 after majority of members voted to change the name of the association to the 'American Association on Intellectual and Developmental Disability (AAMR FYI, July 2006). The new name will be effective from 1st January 2007 the report stated. Ironically the AAMR has updated the definition of mental retardation ten times since 1908, but all attempts to change its name failed till now. So what happened to the AAMR's ethical responsibility all these years?

After reviewing the literature in 2000, Butz and his colleagues concluded that research on the topic has been inconclusive due to the following reasons. Firstly many mental health professionals perceive that intellectual deficits account for other occurring emotional disturbances and symptoms in the lives of people with ID. Reiss, Levitan and Szysko (1982) coined the term "diagnostic overshadowing" which referred to the phenomenon in which the presence of intellectual disability takes diagnostic precedence over diagnosing coexisting emotional disorders. Secondly some clinicians assume that people with ID are immune from mental illness.

Thirdly many therapists are biased and view the person with ID as lacking the verbal ability to discuss cognitive or psychodynamic concepts, or consider over dependence among people with ID as evidence of an inability to productively resolve transference issues. Finally the dichotomisation of intellectual disability and mental health has also inhibited professional interest. However, there is an emerging literature on the importance of recognising the impact of mental illness on this population over and above the diagnosis of ID, as recent claims made about the efficacy of psychotherapy with people with ID have been promising (Lynch, 2004).

What Can Be Done About Some of The Issues

Case Study – Mary’s Story

Mary is a 35 years old woman with severe intellectual disability. She suffers from epilepsy and lives with her aged mother. Mary has a 10-year-old daughter who has been adopted by her extended family member. She has not seen her daughter for the last four years because the family moved interstate. Mary has been in an abusive relationship for the past three years but some-how managed to escape from her abusive boyfriend. She reported that he raped her and threatened to kill her if she tells anyone that he was a drug dealer. She now lives with her mother, but has not left the house the last six months for fear he would attack her. Apparently her boyfriend left town when her mother reported to the police six months ago, but Mary still thinks he is around and would harm her so has withdrawn from society. Mary is depressed and not sleeping well at night but sleeps during the day. She has not been to work for the past twelve months at the local Salvation Army family store where she is a volunteer. She is sad and talks about the loss of her daughter and over-eats. Mary blames and abuses her mother for forcing her to adopt out her daughter.

Creating a therapeutic relationship with Mary

Conducting therapy with people with ID should reflect the social model of disability by recognising that people with ID have the right to receive services that are designed to meet their needs and personal goals in the least restrictive way (ACT Disability Services Act, 1991). In addition, people with ID have the right to have their privacy respected. Olkin (2002) asserted that the social model places emphasis on access and inclusion, and promotes health and resilience.

The therapeutic perspective that meets the characteristics of the social model in my experience is the integration of person-centred approach and behaviour therapy techniques. Pfadt (1991 cited by Butz et al, 2001 p.46) suggested that combining psychodynamic understanding with an application of behaviour intervention is the best way to do therapy with people with ID. Hurley et al (1996) also suggested that therapy with people with ID needed some modification of the traditional approaches such as simplification of language used by clinician, and the structuring of the session. I used some of the Therapeutic Guidelines Limited’s (2005) communication guidelines for working with people with ID to develop a therapeutic relationship with Mary.

First, I talked to Mary (my client with ID) in a respectfully manner, and established rapport by spending a longer time with her than the usual one-hour session. I explain what was happening to Mary by use of simple words, sentences and concepts, and allow enough time to listen to her response as she has some speech impairment.

Secondly, I focus on Mary’s abilities not disabilities, and utilise her strengths not weaknesses, and involve her in what she could do. And thirdly I communicate with Mary who has complex communication needs, by using repetition, signs, gestures, facial expressions, models, photographs, objects, drawings and art therapy. According to Kuczaj (1990), giving the person the time and the place to draw or to do art work has the potential for self-expression at his/her own pace, creative involvement, and for the development of new skills and awareness towards resilience.

Use of Integrative Approach - Combination of person-centred therapy and behaviour therapy techniques for counselling 'Mary'

Using person-centred approach to build rapport and trust with Mary.

The person-centred approach is based on a humanistic perspective, and was devised by Rogers (1959) who emphasised the provision of a supportive emotional environment for the client to express his or her feelings. Humanism is a philosophy that emphasises the dignity and worth of people and their capacity in ways that enhance them (Zastrow, 1999). I developed a therapeutic relationship with Mary by creating an atmosphere where I encouraged her to play a major role in determining the pace and the direction of her counselling. Rogers (1986) stated that the growth potential of any individual will tend to be released in a relationship, in which the helping person is experiencing and communicating realness, caring, and a deeply sensitive non-judgmental understanding. Person-centred therapy places the emphasis on non-directiveness of the therapist who is intensely mindful to respect and protect the autonomy and self-direction of the client (Brodley, 1986).

My role as a client-centred therapist

Rogers identified three qualities: 'congruence or genuineness', 'empathy', and 'unconditional positive regard' that the counsellor must possess for effective counselling to occur. I was real, genuine, congruent and authentic in my interactions with Mary by self-disclosing I am the mother of a child with ID. Rogers (1986, pp.375-377) stated that "Congruence in the therapist's own inner self is his sensing of and reporting his own felt experiencing as he interacts in the relationship."

Empathy is experiencing *Mary's* world as if I were Mary. Ivey and Ivey (1999) referred to empathy as moving into the client's frame of reference, and being able to convey to the client that you are sensing what he or she is feeling. By unconditional positive regard, I show and communicate respect, warmth, acceptance, liking, and caring for Mary despite her behaviour. Unconditional positive regards according to Ivey and Ivey (1999) is the counsellor having a non-judgemental attitude and suspending his/her opinions and attitudes and assuming value neutrality with regards to his/her clients. This creates a comfortable atmosphere for the person to express their feelings.

People with ID have been oppressed and discriminated against over the years, so being empathic, non-judgemental and genuine to them would boost their self-worth and dignity as human beings. For example Joe, Sally and Mary all wanted their counsellors to sense their pain, respect and accept who they are and listen to their feeling before trying to modify their behaviours. Natalie Rogers (1997, cited by James and Gilliland, 2003) recommends person-centred therapy as a premier method for providing "a rare quality to be heard and a spiritual awakening" in children, adolescents, adults, addicts and people with ID.

Limitations of person-centred approach: While working with Mary, I found out some limitations to the person-centred approach, which could affect the benefits in providing counselling and psychotherapy to people with ID. The first limitation is its non-directiveness, as some people with ID may need directions to help them make decisions due to their impaired intellectual functioning (Corey, 2005).

Another limitation of the person-centred therapy is that being an insight approach, it seeks to increase the client's awareness and understanding of the problem without focusing on ways to resolve the problem (Zastrow, 1999). For example after explaining to Mary the causes of her behaviour (which are around post-traumatic stress, and loss and grief issues), it would have been very sad if I left her with no solutions.

Due to these limitations of person-centred therapy, it is therefore useful and appropriate to integrate person-centred therapy with behaviour therapy when providing counselling and psychotherapy to people with ID.

Using Behaviour approach to help Mary change her reactions to crisis.

The history and practice of the behaviour approach can be divided into two components. The first is *classical or respondent conditioning* based on the work of Pavlov (1960) and Hull (1943) (James and Gilliland, 2003). In practice, respondent conditioning is called behaviour therapy that is used to treat a variety of disorders such as affective, (depression), anxiety, substance use, and eating disorders (Corey, 2005).

The second component is *operant conditioning* based on the work of Skinner (1953) and in practise called behaviour modification (James and Gilliland, 2003). Operant conditioning involves a type of learning in which behaviours are influenced mainly by the consequences that follow them. Behaviour modification is an approach to assessment, evaluation and behaviour change that focuses on the development of adaptive, prosocial behaviours and decrease of maladaptive behaviour in daily living (Kazdin, 2001). History reveals that counselling and psychotherapy for people with ID over the years has been limited to assessment and behaviour modification, which reflected the medical model of disability (Baroff, 1986).

However with the social model of disability, there is the need for both behaviour therapy and behaviour modification. For example Joe, Sally and Mary need help to cope with their loss, anxiety and depression, as well as techniques to change their maladaptive behaviours. Behaviour therapy is an action-oriented approach and learning is viewed as being at the core of therapy. The goals of therapy are to acquire new coping skills and create new conditions for learning (Corey, 2005).

My role as a behaviour therapist

The behaviour therapist tends to be active and directive and functions as a consultant and problem solver (Miltenberger, 2004). I conducted a thorough functional assessment to identify the maintaining conditions of Mary's problem behaviour, which were no social activity but total isolation for six months, and the use of food for comfort.

I formulated initial treatment goals, which were arousal reduction techniques, stress management skills, coping skills, return to work, and building a social network. I then designed and implemented a treatment plan of weekly session of counselling, coaching, modelling and structured practice and activities to accomplish these goals. The main strategies and techniques I employed to promote generalization and maintenance of behaviour change were relaxation training, assertion training, artwork, loss and grief counselling and systematic desensitisation.

I evaluated the success of the change plan by measuring progress towards the goals throughout the duration of treatment and conducted follow-up assessments. After six months of hard work and perseverance, Mary is able to deal with some of her losses and is coping better, sleeps well and had since return to work and has started making friends.

Therapeutic Techniques

Behaviour rehearsal is used in connection with modelling, coaching and structured practice with clients, and the role of the counsellor is to help the client practice and perfect the goal behaviours that are similar to the situations that occur in the clients environment (Wilson, 2005).

Assertion training: Assertive training originally developed by Wolpe (1958) and Alberti and Emmons (1970) has come to be the most frequently used method in modifying unadaptive interpersonal behaviour (Zastrow, 1999). The goals of assertion training is to empower clients actively to initiate and carry out desired choices and behaviours that do not harm other people physically or emotionally, and to teach client alternatives to passive, helpless, dependent, and stifled ways of dealing with life situations (James and Gilliland, 2003).

Relaxation Training: Relaxation training targets rapid breathing and muscle tightening which are the two major physiological components of excessive tension and anger, through deep breathing and muscle relaxing exercises (Hepworth, Rooney and Larsen, 1997). Numerous studies have reported that relaxation training has been used successfully to assist clients with problems related to anxiety disorders and moderate depression (Hepworth et al, 1997).

Systematic Desensitisation, a procedure also developed by Wolpe (1958) based on the principle of respondent conditioning is a form of exposure therapy, although time consuming, is effective and efficient treatment for anxiety-related disorders and phobias (Cormier and Nurius, 2003). Clients engage in a behaviour that competes with anxiety, and systematically become less sensitive to the anxiety-arousal situation (Corey, 2005).

Limitation of behaviour therapy to people with ID: Like the client-centred approach, there are some aspects of behaviour therapy, which could negatively affect the benefits of providing counselling and psychotherapy to people with ID. Behaviour therapy may change behaviours, but it does not change feeling (Corey, 2005) and that is why I initially focused on Mary's feeling and then worked on her behaviour.

Secondly behaviour therapy treats symptoms rather than causes (Corey 2005, p.261). Treating symptom reflects the medical model of disability that oppressed people with ID, so the best approach is to treat both causes and symptoms.

Thirdly I realised that I controlled and manipulated Mary through the structured practices and activities I used to change her behaviour. Kazdin (2001) argues that there are no issues of control and manipulation associated with behaviour strategies that are not raised by other therapeutic approaches. However in my experience people with ID could be vulnerable to the directive approach of behaviour therapy and therapists have to be aware of this. As a result of the shortcomings of behaviour therapy, combining the techniques with person-centred therapy is essential as the two approaches compliment each other and provide a positive outcome for people with disabilities.

Conclusion

This article has discussed some of the ethical issues associated with counselling and psychotherapy for people with intellectual disability. This article also looked at what is available for people with intellectual disability and echoed the results of previous studies as therapists are poorly trained in dealing with intellectual disability issues, therapy mainly restricted to behaviour modification which focuses on behaviour and neglects feelings and as a result not suitable for trauma and loss and grief issues. Using a case study approach, I have demonstrated in this article the benefits of using an integrated approach for counselling of a person with intellectual disability with loss and grief, and trauma issues. However more research is needed using the case study approach with a larger and more widely represented population of clients with intellectual disabilities using different integrated approaches to determine which approach yields best results.

The way forward for the field

As counsellors and psychotherapists, do we meet our ethical obligations when working with people with intellectual disability? If the answer is 'NO', then we are failing this population group. As such the main issue is the need for us (counsellors and therapists) to be trained in disability issues in order to provide effective services for this population. The training would provide awareness and assist us determine what we are doing wrong and how we can become more professionally responsible by learning to manage the therapeutic relationship, structure of the session and decide on the duration of therapy for this population group.

Another issue this article raised is the lack of literature on the topic, although the situation is improving, there is the need for more research to be conducted on the benefits of counselling and psychotherapy with this population using different techniques other than behaviour modification.

The way forward for the field (particularly in Australia) is to respect the rights of people with intellectual disability, to include them as a minority group when emphasising diversity and cultural differences, and to incorporate the disability discipline into the core of curricula and research programs. By doing this the profession will meet its ethical requirements as proclaimed in the 'Declaration on the Rights of Disabled Persons' 1975.

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