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Counselling Services for Adults with an Intellectual Disability:

Implications for Counselling

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Abstract

The counselling needs of adults with an intellectual disability are similar to those of other counselling clients. These adults, however, face a number of barriers that restrict their access to effective counselling. In this paper, we use an exploratory study to discover how counsellors, counsellor educators and support workers perceive these barriers. The findings are discussed in relation to existing literature and the implications they hold for counselling practice.

Introduction

Counsellors seek to uphold the values and ethics of their profession. They strive to act with care and respect for individual and cultural differences and the diversity of human experience. They work to increase the range of choices and opportunities for clients and do their best to practise within the scope of their competence (NZAC, 2002, p. 26). Counselling New Zealand adults with an intellectual disability challenges each of these principles. Very few counsellors have experienced the special schools and the institutional living so common for this client group. In addition, the myriad barriers that develop between the goals and the lived experience of these clients challenge counsellors' attempts to help them increase choices and opportunities. Furthermore, while counsellors want to work competently and sensitively with this vulnerable group, local information on best counselling practices is scattered across disciplines. Therefore, counsellors may have difficulty accessing relevant information. Local articles that discuss issues relevant to counselling include Chapman and Pitceathly (1985), Larkin (1992), Mirfin-Veitch (2003b) and Winslade (1994).

This paper reports on the findings and implications of a small, exploratory research study about local conditions affecting the place of counselling for adults with an intellectual disability. Central to the study are the views of counsellors, support workers and counsellor educators about the effectiveness and accessibility of professional counselling services for adults with an intellectual disability.

Background: the development of separate "worlds" in the New Zealand context

Early in the exploratory study, the separateness between counselling and disability became obvious; a separateness that mirrors what has existed for many years between the lived-worlds of any minority group and the mainstream community. This situation often reflects the outcomes reached when governments struggle to meet the challenges posed by the needs of people who are "different", while simultaneously attempting to meet the needs of the mainstream majority.

Communities respond to these differences by providing either segregated services or services that are mainstreamed. Segregated services offer minority groups an opportunity for specialised services targeted toward their specific needs, but they also run the risk of isolating and marginalising the minority group. Mainstream services offer minority groups an opportunity for fuller community participation but they also run the risk of reducing specialised knowledge about the minority group.

In the early 1900s the New Zealand government began funding supports specifically for those with disabilities. The government established and funded large institutions which "were typically located in isolated rural areas and operated self-sufficiently, away from other residential or commercial activity" (Office for Disability Issues, 2002). From age five onwards those who were classed "mentally defective" were expected to live in psychiatric hospitals under the responsibility of the Director General of Mental Defectives (Millen, 1999).

This segregated response continued through until the 1960s with some minor changes. For example, in 1929 the first psychopaedic institution, Templeton Farm and School, was established to provide residential care for children with disabilities. Psychopaedic institutions were an alternative to psychiatric hospitals but were nonetheless still segregated services. Many New Zealanders continued living in psychopaedic institutions until community resettlement projects began in the 1990s. The last of the psychopaedic resettlement projects is expected to be completed in 2005.

Although residents of psychopaedic institutions continued to live apart from the mainstream community until this past decade, the mid-1960s witnessed the beginning of changes where options for the provision of community-based services were explored and introduced. The Education Act 1964 provided for special classes, clinics or service in connection with primary, secondary or other institutions. Then, in 1975, the Disabled Persons Community Welfare Act was passed to:

> *make better provision for financial and other assistance in respect of the disabled, and for the support of voluntary organisations and private organisations concerned*

> *with providing facilities for the community welfare, sheltered employment, training, and day care of disabled persons (Disabled Persons Community Welfare Act 1975).*

Following the 1988 Tomorrow's Schools reforms, the 1989 Education Act established the Specialist Education Service (Ministry of Education, 2002) and included legislation for the rights of children with an intellectual disability to attend their local school. Future amendments paved the way for more recent initiatives including the development, in 2001, of the New Zealand Disability Strategy. Its aim is to promote a society that values those with disabilities and enhances their full participation in the community (Dalziel, 2001). Alongside this strategy, the National Health Committee conducted initial research to explore aspects of the lives of adults with an intellectual disability. Their definition of an intellectual disability was:

> *a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood with a lasting effect on development* (Department of Health (UK), 2001, p. 14).

The National Health Committee's research included details about their living situations, transportation, health and medical care, employment, leisure time, and communication. The findings, published in a report called *To Have an "Ordinary" Life*, demonstrated the difficulty these adults have participating fully in the community. They so often face barriers in their attempts to achieve the "ordinary" goals that are often taken for granted.

> *Their lives are very different from other New Zealanders and are not consistent with the visions of the New Zealand Disability Strategy* (National Health Committee, 2003, p. 6).

The report also identified a need for more information about effective ways to provide support for this population.

> *Research in the New Zealand context is needed to identify the unmet needs of people with an intellectual disability and to identify the barriers to meeting these needs. Current policy and funding structures are not well designed to provide intermittent or tailored support services to individuals with milder degrees of disability. Generic systems are also usually uninformed about intellectual disability and often fail to identify and meet the needs of people with an intellectual disability, particularly those whose difficulties are exacerbated by environmental stressors* (Bray, 2003, p. 22).

Although a number of services that support adults with an intellectual disability were mentioned in this report, counselling was noticeably missing. It was for this reason that the first author decided to explore the availability and effectiveness of professional counselling services for this client group.

The study

Possible research participants

The present study was conducted in Christchurch, New Zealand. Four distinct groups who could provide valuable information were identified – adults with an intellectual disability, support workers, counsellors, and counsellor educators. Support workers were defined as people whose jobs give them face-to-face contact on a regular basis with adults with an intellectual disability. This diverse group includes, but is not limited to, social workers, psychologists, carers, chaplains, community workers, needs assessors and service providers. Counsellor educators were defined as people who teach at a tertiary institution which offers education that leads to a diploma, certificate or degree in counselling. Because many psychologists also practise counselling, counsellor educators also included educators at a tertiary institution which offers education that leads to becoming a psychologist. Since the term counsellor is not registered or protected in New Zealand, counsellors were self-defined.

Ethical considerations

When designing a research project that discusses the needs of a specific client group, a researcher must carefully consider how best to involve that group in the research. This is particularly important when discussing the needs of marginalised groups whose voices are often ignored. New Zealanders with an intellectual disability are a vulnerable group whose voices are important for such a study. Their knowledge and experience is invaluable, yet obtaining informed consent from them raises a number of ethical questions.

First, since people with an intellectual disability often have fewer opportunities to acquire ordinary knowledge, how can the researcher be assured that they understand abstract concepts such as confidentiality, anonymity and research? Second, how does the researcher determine that sufficient time and opportunities have been provided to enable participants to comprehend the terms and implications (Lindsey, 1994, as cited in Bray, 1998)? Third, how does the researcher determine that their consent is not a form of acquiescence to the requests of people perceived to be in authority (Bray, 1998)? When these questions were considered, the first author recognised that, given the short time frame for the study, it would be unethical to rush the participation of

New Zealanders with an intellectual disability in this particular study. The hope is that findings from this study will inform and encourage future researchers to include this client group in related studies.

Method

Participants and procedures

Ethical approval from the University of Canterbury Human Ethics Committee enabled the first author to invite support workers and counsellors to complete a questionnaire, and counsellor educators to be interviewed. Support worker questionnaires (113) were distributed to agencies that provide specialised support services for clients with an intellectual disability, to residential service providers, and to agencies that provide support for a wide range of disabilities including intellectual disabilities. Twenty-five support worker questionnaires were returned, a 21.2% return rate. Twenty-four percent of the respondents were male; 76% were female. They ranged in age from 27 years to 54 years; the average age was 41 years. Seventy-six percent of the support workers had five or more years of experience. Eighty-eight percent of the support workers had received training for working with adults with an intellectual disability.

Counsellor questionnaires (79) were distributed to generic counselling agencies, counselling agencies for specific target groups, social service agencies that provide counselling as part of their service, and individual counsellors. Forty-eight counsellor questionnaires were returned, a 60.7% return rate. Thirty-three percent of the respondents were male; 67% were female. They ranged in age from 30 years to 77 years; their average age was 50.6 years. Sixty percent of the counsellors had five or more years of experience. Eighty-one percent of the counsellors were members of a professional organisation.

Five counsellor educators from five different tertiary programmes were interviewed. Two programmes were at Masters level and three at Diploma level.

Findings

The questionnaires were constructed around key themes that arose in the literature. The following sections compare findings from both the literature and the present study.

1. Do many adults with an intellectual disability have reasons to seek counselling?

New Zealanders access professional counselling for a variety of reasons. Manthei and Duthie (2003) identified that the most common reason clients of a Christchurch counselling agency sought counselling was relationship or family problems. Other common reasons were depression, personal growth, anxiety and anger/abuse.

New Zealanders with an intellectual disability experience similar issues (Larkin, 1992). Though the National Health Committee's report does not specifically mention counselling needs, relationship issues and personal growth needs are embedded in their report.

> *People with an intellectual disability often need support to make and maintain relationships. This support can vary from practical help … through to learning and understanding about relationships and the things you need to do to make them work* (National Health Committee, 2003, p. 38).
>
> *The National Health Committee recommends that the potential for adults with an intellectual disability to grow and develop through their lives be recognised* (National Health Committee, 2003, p. 37).

Similar counselling needs are found overseas. In the United States, Wittmann, Strohmer and Prout (1989) surveyed counsellors who worked with clients with borderline/mild intellectual disabilities about the most common problems for which this client group sought help. The problems listed most commonly were interpersonal concerns, general psychological functioning and work. Hodges (2003), in the United Kingdom, mentioned common presenting problems such as abuse, bereavement and loss, and challenging behaviour.

While the range of mental health needs of adults with an intellectual disability appears similar to those of the general public, prevalence similarity is more contentious. A common view is that the prevalence of psychopathology is higher in those with an intellectual disability than in the general population (Harum, 2001; Sevin & Matson, 1994). Yet other reports contend that the prevalence of those needs is similar to the general population (Beail, 2003; Hatton, 1998). The National Institute of Mental Health (2000) stated that the manner in which data are collected greatly influences the prevalence estimates.

To obtain some prevalence indication in this present study, support workers were asked the following two questions:

> *People seek counselling for issues such as grief, depression, anxiety, and relationship difficulties. In your opinion, about how many adult clients have you worked with in the past month that might benefit from counselling?*
>
> *How many of those clients did you refer on to a counsellor?*

Their responses varied widely in their estimate of clients' needs, ranging from zero clients with counselling needs to nearly all clients with counselling needs. Seventy-six

percent (19) of the support workers worked with clients who they considered might benefit from counselling, but they did not consistently refer those clients to a counsellor. Table 1 shows the contrast between the number of clients who might benefit from counselling and those who were referred on to counselling.

Table 1: Estimates of clients' counselling needs and subsequent referrals

No. of support workers noticing needs	Perceived no. of clients who might benefit from counselling	Actual no. of clients referred to counselling or already in counselling
1	This is not an area I have considered	(Left blank)
4	0	0
4	1	0
1	More than 1	0
1	1	1
2	Residential work/ cannot quantify	1
2	2	0
2	2	1
1	2	2
1	3	0
2	4	0
1	5	1
2	40–50%	"Service combines counselling behavioural issues" and "more when I had clear referral process"
1	All	80%

2. Is counselling an effective way to address the mental health needs of these adults?

Historically the approaches used to treat distressed adults with an intellectual disability focused on pharmacological intervention or behavioural approaches (Caine & Hatton, 1998; Hodges, 2003; Moss, 1998; Prout & Strohmer, 1994; Sevin & Matson, 1994). This may explain why there are few published evidence-based research studies on counselling effectiveness for this group (Beail, 2003; Hodges, 2003; Prout & Nowak-Drabik, 2003). Perhaps counselling is often overlooked as a treatment option for this group.

In the present study, responses from support workers and counsellors suggested that counselling is indeed sometimes overlooked as a treatment option. One counsellor wrote:

> *Problem gambling can be a pitfall for people with intellectual disabilities – and it is not always picked up or addressed by agencies that specifically deal with these clients.*

And another wrote:

> *I suspect that in some counselling organisations there may be a tendency to trivialise the counselling issues of people with intellectual disabilities.*

Overlooking counselling as a possible treatment option and relying solely on pharmacological interventions can lead to disturbing practices.

> *For instance, 40 percent of people being treated with psychotropic medicines had never been diagnosed as having a psychiatric condition. It appears that in many cases medications are being used to deal with behavioural problems, rather than the cause of the behavioural problem being addressed* (National Health Committee, 2003, p. 25).
>
> *The NHC therefore recommends that the systemic neglect of the health of adults with an intellectual disability be urgently addressed* (National Health Committee, 2003, p. 26).

While research on counselling effectiveness often fails to mention this client group, many practitioners who are working with these clients consider counselling to be an effective service (Caine & Hatton, 1998; Gallagher, 2002; Larkin, 1992; Prout & Nowak-Drabik, 2003). Here is what Michael, a 32-year-old with an intellectual disability, said about his counselling experience:

> *It helps you find better ways to act … helps you to know about other people and why they act funny … Someone you can tell things to and they won't always be on judging you – and they won't blab it around* (Prout & Strohmer, 1994, pp. 16–17).

In the present study, counsellors, too, suggested that counselling can be an effective service for these clients. Their comments in questionnaires included:

> *I have worked very successfully with a number of clients who have had intellectual impairment in some capacity.*
>
> *The rare opportunities that I have had to work with people with an ID have been rich and rewarding.*

However, in order for counselling to be an effective treatment option, it needs to be accessible to this client group.

3. Do adults with an intellectual disability face barriers that hinder their access to counselling services?

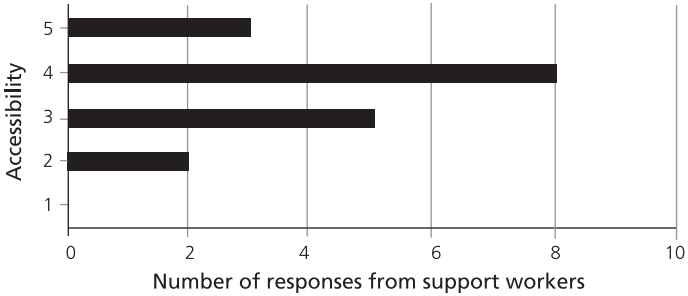
Attitudinal barriers, physical barriers and financial barriers can hinder access to counselling services. While Manthei and Duthie (2003) indicated that the public holds a generally negative view towards seeking psychological help, they also note that New Zealanders do seek counselling. Manthei (2004) noted that 13 of the 31 clients in his study were convinced to go to counselling on the advice of someone else. As noted above, historically adults with an intellectual disability have not received advice to seek counselling when they are feeling distressed. Rather, they have been issued with preferred medical or behavioural interventions (Sturmey, 2005). In the 1980s, however, several authors began consistently promoting counselling as a treatment option for this client group (Hurley & Hurley, 1986; Matson, 1984; Tharinger et al., 1990). However, a significant barrier is the slow change in knowledge and attitudes of family members, or support workers who often overlook or minimise the feelings of distress of people with an intellectual disability (see, for example, Ng et al., 1995).

Once a client has decided to seek counselling, transportation is a potential barrier. Adults with an intellectual disability are a diverse group. Some are able to drive, while others have more complex mobility needs. The National Health Committee (2004) cited a survey by Fitzgerald and Associates (1999) where people with an intellectual disability identified transport as their highest priority need. Another possible barrier is the cost of counselling. "Most people with an intellectual disability rely on income

support to meet the costs of everyday life" (Mirfin-Veitch, 2003a, p. 27). Although clients on a low income can access the disability allowance to pay for counselling, many of these adults use the disability allowance to pay for other expenses (Mirfin-Veitch, 2003a).

In the present study, support workers were asked, "In your experience how accessible are counselling services for your clients?" Most responded that accessibility was difficult (Figure 1).

Figure 1: Support workers' views of counselling accessibility



5 = Access seems impossible
3 = There are several barriers, but with extra effort counselling can be accessed
1 = Very easy to access

The three barriers most commonly mentioned by support workers were lack of funding:

> … *funding also often an issue unless accessed through ACC* …

lack of trained counsellors:

> … *there are very few counsellors that can effectively deal with a lot of the issues that our people need support with.*

and communication difficulties. Support workers expressed concern about counsellors' abilities to understand their clients' ways of communicating.

> … *people with disabilities have extremely diverse and complex needs and ways of communicating* …

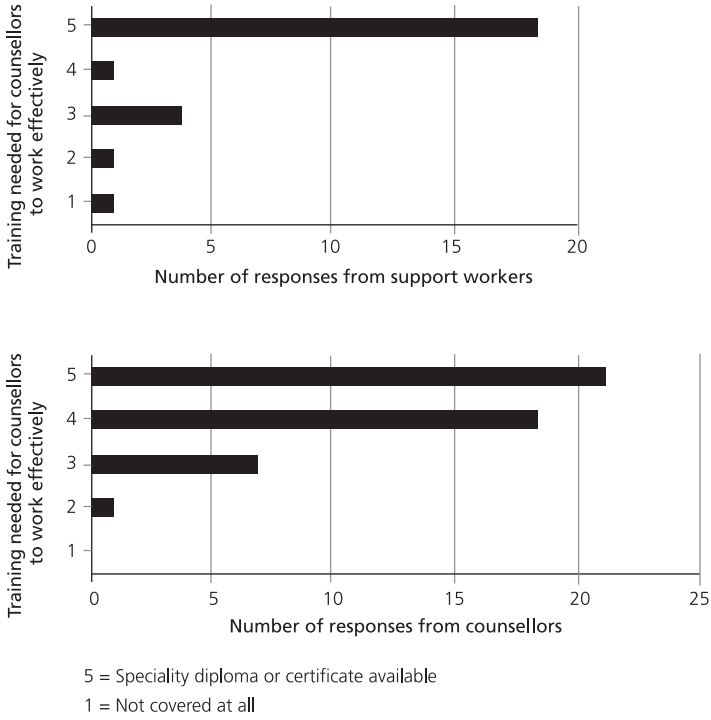
Support workers also expressed concern about the communication difficulties in

the counselling referral process:

… so much red tape.

The three barriers most commonly mentioned by counsellors were cost of counselling, lack of trained counsellors, and difficulties clients might have in completing the series of steps involved in finding a counsellor, making the appointment, and arriving at the office. Both support workers and counsellors indicated that the lack of specialist-trained counsellors might be a barrier. When asked whether specialised training was necessary for counsellors to work effectively with adults with an intellectual disability, both groups considered this essential (Figure 2).

Figure 2: Views on training needed for counsellors to work effectively



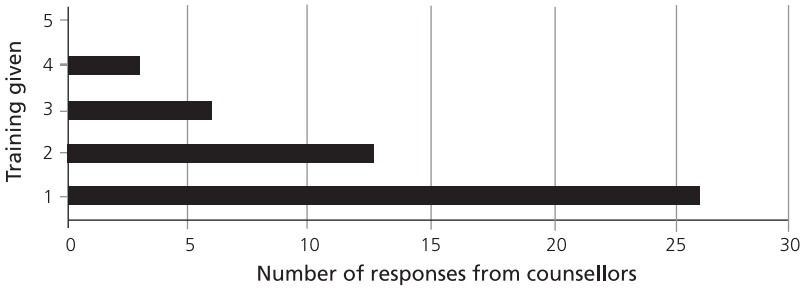
Assuming that a client is able to surmount these barriers and engage in the counselling process, we are left with the following question.

4. Are counsellors informed about intellectual disabilities?

In many countries, students receive specialised counsellor education in the area of disabilities through tertiary level rehabilitation counselling programmes. Where this field is well-established, there are active professional associations especially for rehabilitation counsellors. In New Zealand, however, rehabilitation counselling is not well-established and, as Hornby (1994) and Olkin (2002) have noted, the topic of disabilities is often not covered in generic counsellor education programmes.

In the present study, counsellors were asked to consider their tertiary counselling training and answer the question, "How thoroughly was the topic of intellectual disabilities covered in your training programme?" Their responses, gathered in Figure 3, indicate that a discrepancy exists between their views that specialist training is needed to work effectively with this client group (Figure 2) and the level of training they have received (Figure 3).

Figure 3: Counsellors' views of their training



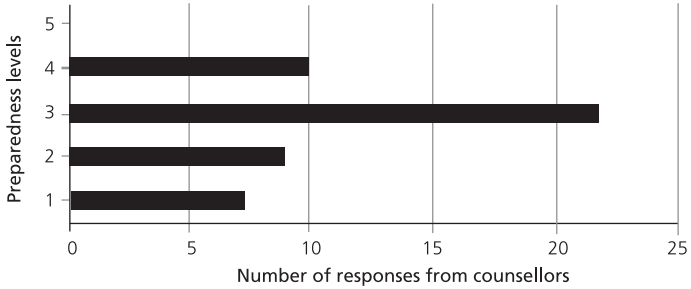
5 = Speciality diploma or certificate available
1 = Not covered at all

Counsellor educators were asked whether their programmes covered the topic of intellectual disabilities. Two programmes have specific content sections in the curriculum on intellectual disabilities. One programme requires students to present seminars about disabilities, including intellectual disabilities. One programme does not cover intellectual disabilities in a specific way, rather the topic is taught in bits and pieces throughout the course and specific techniques are taught about how to modify the work so it is manageable for these clients. Another programme does not specifically cover intellectual disabilities, but expects it to be covered briefly in a reading or by a particular student interest.

Many counsellor educators mentioned that students were viewed as motivated, self-directed or "active" learners. They explained the lack of formal content on working with clients with an intellectual disability in their comments about not being able to "teach everything". Furthermore, they considered that it was sufficient for students to be able to pursue individualised learning in specific areas of their choice and extend their learning in their placement and clinical supervision.

Formal training is not the only way that counsellors inform their practice. Professional development, training in other areas and life experiences also play a large part in a counsellor's ability to provide an effective service. The counsellors were asked to consider all their training and life experiences when answering the following question: "How well do you feel that your training and your life experiences have prepared you for counselling an adult with an intellectual disability?"

Figure 4: Counsellors' views of their preparedness



5 = I feel well prepared to counsel this client
3 = I feel outside my comfort zone, but would do my best to work with the client
1 = I do not feel well prepared and would prefer to refer the client on

Their responses (Figure 4) suggest that counsellors rely on their life experiences to compensate for limited specialist education. When asked to elaborate, most counsellors considered that specialised training would increase their effectiveness.

> *Not having had specialised training, the "learn as you go" technique is far inferior to formal training if it has been given.*
>
> *Counselling is a very diverse profession. Specialised training always enriches the counsellor to work with either specific groups and/or specific issues.*

Discussion and recommendations

This study investigated the views of Christchurch counsellors, support workers and counsellor educators on the accessibility and effectiveness of counselling for adults with an intellectual disability. The findings support the literature which suggested that counselling could be an effective service for adults with an intellectual disability (Caine & Hatton, 1998; Gallagher, 2002; Larkin, 1992; Prout & Nowak-Drabik, 2003). The findings also mirror the literature which indicated that attitudinal, financial and physical barriers often hinder access to counselling services (Hodges, 2003; Mirfin-Veitch, 2003a; Moss, 1998; Prout & Cale, 1994; Prout & Strohmer, 1994) and that generic counselling education programmes may fail to include the topic of disabilities (Hornby, 1994; Olkin, 2002).

While the study is small, local and dependent on self-reported opinions (rather than actual practice) of participants, its strength lies in the diversity of participants' roles – support worker, counsellor and counsellor educator. Sadly, it does not include the voices of people with an intellectual disability, and this lack of voice also mirrors their lack of voice in counselling effectiveness literature (Beail, 2003; Hodges, 2003; Prout & Nowak-Drabik, 2003). Furthermore, this study also fails to include family members of those with an intellectual disability.

Despite these limitations, the findings raise some important implications for counsellors and the counselling profession.

Implications

The most notable implication is the need for more information on how best to address the counselling needs of adults with an intellectual disability. A support worker with 15 years' experience described how counselling research would be a good initial step.

> *I feel that counselling is still a very young discipline that needs ongoing research. I find that nowadays life is becoming increasingly complex, and when it comes to people with disabilities, we need huge compassion and even huger empathy to try and develop perceptions that will allow us to develop the respect needed in that work.*

We believe it behoves the counselling profession to find ways to initiate and support collaborative research that includes adults with an intellectual disability, and that focuses on effective ways to improve counselling services to this client group. We hope that this article will provide the motivation for such research to occur.

The findings of this study also suggest that counsellors who are working with people with an intellectual disability need to find creative strategies to help improve accessibility for their clients. Along with this, counsellors need to find ways to advertise the effectiveness of their work with this group and support workers need to increase their awareness of the benefits of counselling and of times when counselling might be helpful for their clients. Support workers have specialised knowledge that could benefit counsellors, and counsellors have skills that could benefit the support workers' clients.

Perhaps the first step would be collaborative seminars in which all the stakeholders –people with an intellectual disability, their family members and support workers, counsellors and counsellor educators – shared their knowledge and skills. An example of such a gathering occurred in Washington DC in September 2005 (Alliance for Full Participation, 2005). In New Zealand the counselling profession has an opportunity to model fuller community participation as well as to address counsellors' needs for specialised education by supporting such collaborative seminars.

One disturbing finding is the lack of formal specialised training in counsellor-education programmes. An obvious implication of this is the need for counsellor educators to find ways to address the perceived need for specialised training in effective counselling with people with an intellectual disability. This may require minor shifts in the focus of the curriculum, and again the inclusion of personnel with specialised expertise.

It may be difficult to bring about changes in practice. Limited resources are a reality mentioned by support workers, who mentioned overloaded resources and/or long waits, and by counsellor educators, who expressed limitations of time and resources. In spite of these difficulties, however, we believe that counsellors (ourselves included) need to uphold the commitment "to the equitable provision of counselling services to all individuals and social groups" (NZAC, 2002, p. 27) and look for ways to change current practices. The results of this small study highlight an awareness of the need and commitment to improve counselling services for adults with an intellectual disability. When a forum is created for all stakeholders to work together, positive changes will occur.

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