

**Brainstorming collaborative solutions:
Looking back at problems but moving forward to find collaborative ways to better
support the emotional and mental well being of people with an intellectual disability**

By Marilyn Raffensperger
Disability Support Workers Conference
Melbourne 2010

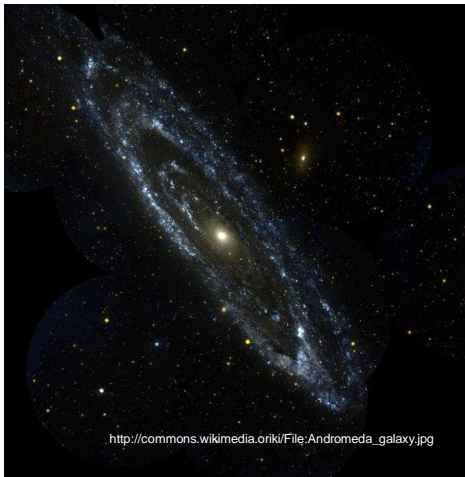
Good afternoon. I am a researcher at the University of Canterbury and I am a counsellor. Many people come to presentations thinking that the person giving the talk is the expert. I come to presentations wondering about the expertise of the people sitting in the chairs listening to the presenter. Before I begin this presentation I would like to know your areas of expertise.

Here is a brief outline of this presentation:

- Acknowledgments
- Reasons for doing this research project
- A description of the project
- Some problems identified in this research
- Discussion about how we can pool our expertise to respond to these problems

Acknowledgments

This presentation is based on my doctoral research at the University of Canterbury. I have many people to thank. First of all, I would like to give honour to God, the creator of this diverse universe. God spoke into being expansive galaxies and tiny one celled creatures and loves each one of us.



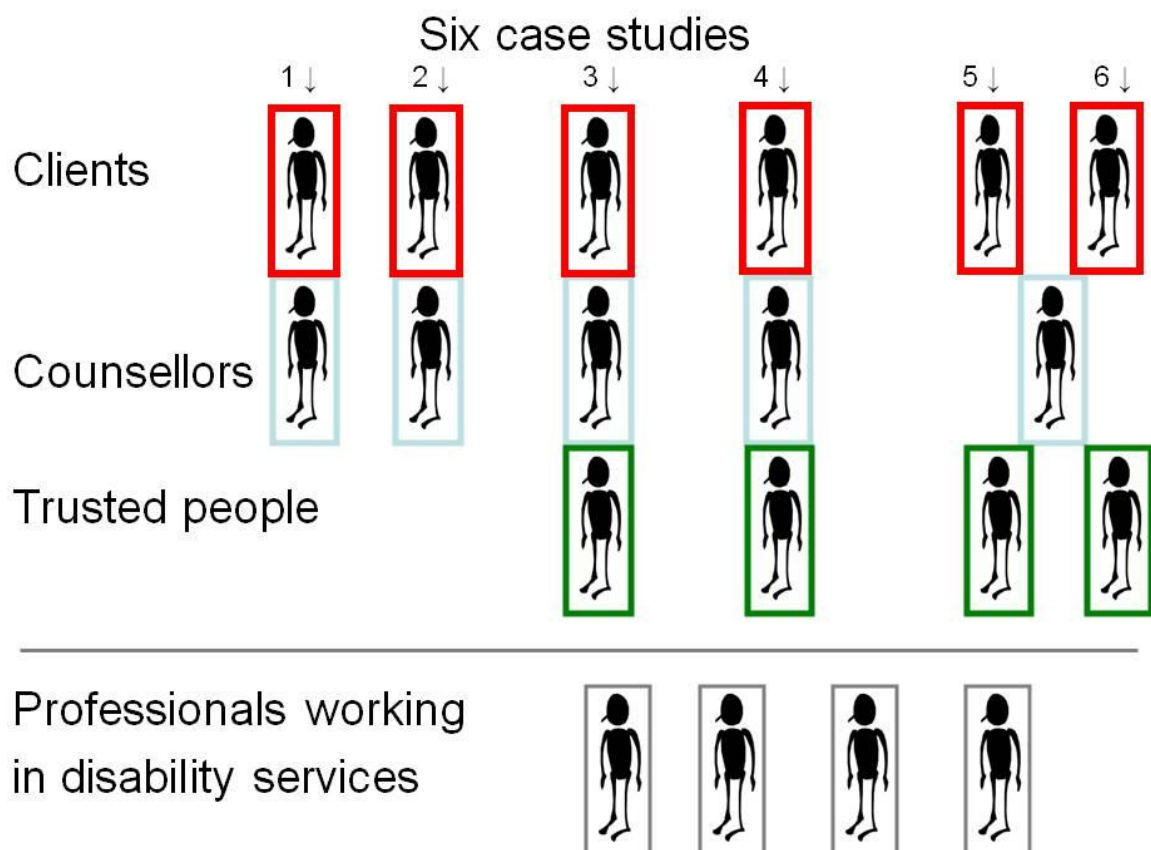
I would like to express many thanks to my supervisory team: Associate Professor Judi Miller, Dr. Brigit Mirfin-Veitch, Professor Garry Hornby, Professor Bob Manthei, and Associate Professor Anne Bray. I would also like to thank: Trish O'Donnell, a mentor, Marjorie Hunt, my clinical counselling supervisor, the University of Canterbury, the Health Research Council, the University of Canterbury Human Ethics Committee, the Upper South B Ethics Committee, the College of Education, especially the research community on the fifth floor of Tower, my family and friends, and the 19 research participants.

Reasons for doing this project

Many people with an intellectual disability have emotional needs or mental health needs that are ignored, overlooked or put into the “too hard basket.” However, the emotional and mental well being of people, is far too important to be left to wilt in the “too hard” basket. Counselling is one way of looking after people’s emotional needs and mental health needs. It isn’t the only way, but it is one choice that people in New Zealand can have. Unfortunately, sometimes it is difficult for people with an intellectual disability to get counselling. Because I am a counsellor, I wanted to know what counsellors could do in response to these problems. So I wanted to learn more about what counselling was like for clients with an intellectual disability.

A description of the project

The purpose of this project was to explore counselling from the point of view of counselling clients with an intellectual disability, counsellors and people outside of the counselling process. The project was designed as six case studies. Six of the participants were clients with an intellectual disability. Five were their counsellors. Four were trusted people chosen by the clients. (Two clients chose not to include a trusted person in the study.) Two of the people were family members. One was a friend and one was a paid support worker.



As you can see, Case 5 and Case 6 have different clients and different trusted people, but the same counsellor. Multiple interviews were conducted with each of the participants over a several month period. As the study progressed I wanted to learn more about local disability support services. So I also conducted single interviews with four professionals who worked in disability services. The interviews were transcribed and then analysed.

Analysing the data

One way I organised the data was to think about the counselling process.

I think of counselling as starting with some kind of problem or reason for thinking about counselling. Once a problem has been identified and a decision is made to seek counselling, the next step is to find a counsellor. I have called this step the referral process. Next the person meets with the counsellor to try and sort out the problems or issues. I have called this step “engagement in counselling.” When the client and counsellor have finished working together, there is a process of ending the client/counsellor relationship. During the counselling process, both the client and the counsellor are hoping for some positive outcomes.



The counselling process

This afternoon I will just be talking about the first two stages: Identifying counselling issues and the referral process.

Identifying counselling issues

In this study the six clients were receiving counselling for common counselling issues such as depression, job loss, anxiety, relationship problems, OCD, worries about money, suicidal thoughts and sexual problems. I am curious, what has been your experience in noticing common counselling issues?

An important thing I noticed in this study was that problems looked different, depending on your point of view.

For example, one client in this study was referred to counselling because he had been brushing up against female staff. The family member who made the referral felt that the problem was of a sexual nature. However, from the counsellor’s point of view, the problem was related to the client’s obsessive compulsive disorder. When the client touched things he considered dirty, he then needed to wipe off that dirtiness, so he brushed up against staff. Now the client uses a tissue to wipe off dirtiness. His OCD problem is still with him, but his behaviour is not longer causing problems for the people who are supporting him.

The referral process

I am curious, what has been your experience of referring people to counselling?

Sometimes people decide on their own that they want to see a counsellor. This is called self-referral. Other times, someone else suggests counselling. In this study most of the clients has someone who helped them to get to counselling. According to the Royal College of Psychiatrists (2004). “Self-referral for treatment is very unusual. In a previous database of 160 adults [with an intellectual disability] referred to a therapist at the Tavistock Clinic, none was a self-referral” (p. 39).

In this study problem arose in the referral process for the following reasons:

- Limited finances
- Difficult to find a counsellor
- Prejudice

Brainstorming

I am keen to help support the emotional and mental well being of people with an intellectual disability. But as a counsellor I am usually only involved in the last three stages of the counselling process. There are many problems in the first two stages and sadly many people do not get the chance to see if counselling would help them. I would like to spend the remaining minutes brainstorming with you all about how we can all work together to make the counselling process more supportive.

Support needs identified in this project

The following page summarises the support needs identified by participants in this study.

References

- Raffensperger, M. K. (2010). *Facilitating positive counselling outcomes for clients with an intellectual disability*. Doctoral dissertation. University of Canterbury, Christchurch, New Zealand.
- Royal College of Psychiatrists (2004). *Psychotherapy and Learning Disability* (College Report 116). London: Author.

Presenting problems	Referral process	Engagement in counselling	Termination	Outcomes
<ul style="list-style-type: none"> • A need for more consistent recognition of common presenting problems 	<ul style="list-style-type: none"> • A need for support in finding a suitable counsellor • A need for support in accessing funding for counselling 	<ul style="list-style-type: none"> • A need to support the clients' learning and communication needs • A need for the therapeutic relationship to be warm, friendly and flexible • A need for extra time to establish a working alliance • A need for extra time for the client to take on board new information and to learn new skills • A need for support between counselling sessions • A need for practical support 	<ul style="list-style-type: none"> • A need for creative and flexible endings to the counsellor/client relationship 	<ul style="list-style-type: none"> • A need to support a wide variety of possible outcomes including outcomes intrinsic to the client as well as outcomes external to the client

Support needed during the counselling process

Raffensperger (2010)

Takeaway Menu:

Session Title: Brainstorming collaborative solutions: Looking back at problems but moving forward to find collaborative ways to better support the emotional and mental well being of people with an intellectual disability

Presenter: Marilyn K. Raffensperger

Contact details: +6427 366 5441 or m.raffensperger@gmail.com

Many people with an intellectual disability are living with unaddressed emotional and mental health needs. Counselling is one means of addressing these needs. Unfortunately, it can be difficult for people with an intellectual disability to access counselling. This research project highlighted a number of problems that interfere with the counselling process. These problems include: Poverty, unaddressed health needs, a lack of specially trained counsellors, social stigma, disability support staff shortages and high staff turnover in disability support services.

Counsellors and disability support workers can play key roles in responding to these issues.

By working together and learning from each other, we can better support the well-being of people with an intellectual disability. Thank you for taking time to listen to this research project and for sharing your ideas. This page includes some of my ideas and some blank spaces for writing down the ideas that have been shared today.

- People with an intellectual disability and people without an intellectual disability experience the same range of emotional needs and mental health needs. If you are supporting someone who has experienced a trauma or a loss, it is likely that they will be experiencing an emotional reaction and will be in need of extra support.
- Staff shortages and high staff turnover can make it difficult for support workers to recognise the emotional and mental health needs of the people they are working with. If you are working with a new person who is experiencing problem behaviours or emotional outbursts, maybe something has upset them. Consider spending a bit of extra time learning about their current life circumstances. Consider what support you might like if you were in that situation.
- Many people believe that counselling doesn't work for people with an intellectual disability. Because of this belief, many people with an intellectual disability do not get the opportunity to try counselling.
- Only a small amount of research has explored what people with an intellectual disability have to say about their experiences of counselling. In this study all six clients had some positive counselling outcomes. You may like to read the following article about one person's experiences of counselling. [Note: I will supply this link later. It is not currently showing up on the website. I will email them and find the updated link.]
- If you are supporting someone and you believe that they might benefit from counselling, be prepared that the referral process may be difficult and may take time. If you persist with the referral and find a suitable counsellor, there is a good chance that counselling will be of benefit.

Here is a summary of the ideas that we brainstormed together in this session.

Lack of Counselling Services

- A need for different styles and approaches
- Service providers need training in how to work with people with intellectual disabilities

Knowing when to refer:

- GPs need to know when to refer to counselling
- DSWs need training so DSWs can act and advise "experts" (GPs)
- Training could be included in Cert IV
- Is it a bad day or feeling "down" or being depressed?

What is best: Medication? Counselling? Alternatives?

The process of counselling

- Be aware of cultural differences, for example, acceptability of counselling and acknowledgment of mental health
- Is it too hard or too much work?

What can we learn from other fields, for example from youth work?

Helpful web sites:

<http://www.cds.med.usyd.edu.au/>

<http://www.cddh.monash.org/>

I value your input. If you want further discussion, please feel free to contact me.