History in Practice Project

Past: Medicalized Minds and Spaces of Hope

Title "But Now We Know Better..." by branwen Willow and Cat Omura

(This scenario is based on a true story recounted to us by a friend who had to face this same situation. It is a fictionalized account and the names of the real institution, patient, doctor and family member have been changed. We encourage you to think about your own reaction to this story that really has happened in BC during the large scale de-institutionalization that took place in the early 90s.)

Venue: 1990s BC, Canada

Margaret's modest apartment in Burnaby on the kitchen phone Then in Dr. Howard's office at Happy Pines Institute for the Mentally Deficient

<u>Cast:</u> Margaret Jones, mature single working woman Dr. Howard, neuro-psychotherapist at Happy Pines Institute

Margaret is home putting away groceries when the phone rings.

M:" Hello."

Dr. H:"Hello, is Edith or Jack Jones there please? This is Dr. Howard calling from the Happy Pines Institute for the Mentally Deficient."

M:" I'm Margaret, their daughter. I'm sorry to tell you Edith and Jack were both in a bad traffic accident years ago. They never fully recovered and both passed away 4 years ago."

Dr. H:" I see. I'm so sorry for your loss."

M:" Thank you Dr."

Dr. H:" I need to speak to you about your brother Joseph in our institute. What did your parents tell you about him?"

M: (shocked and in disbelief) "Brother! They never said – are you sure you have the right -? Surely I would have been told if I had a brother?!"

Dr. H.: "Not necessarily. When Joseph was first admitted in 1957, prevailing ideas and attitudes were very different. It was considered unsuitable to try to care for seriously mentally deficient children at home without the experience and training of specialists with the facilities for 24 hour care. And it was considered

too hard, too confusing for our charges to have family visit. There were more behavior problems after they left. Parents were advised to try and move on. In those days, families with these problems were viewed with suspicion or blame. Many never talked about what were considered their family's secret tragedies or admitted they had any "weaknesses" running in the family. The shame and stigma could ruin prospects for marriages or job promotions then. And they often never knew how to tell the children...."

M.: (suddenly realizing) "Oh my god...I have a brother! A mentally ill brother? All this time... Tell me about him Dr. How ill is he? Does he know about me? Can I have a picture of him? Can I visit?"

Dr. H.: "Well, certainly you can see him. In fact, the sooner the better. I think I can fill you in better face to face at my office rather than over the phone..."

<u>Change of Venue</u> to Dr. Howard's office, two weeks later, both sitting at his desk in the middle of a conversation:

Dr. H.: "...And as our facility is closing, we need to establish new placements before we tell the patients they are moving to minimize any anxiety they might feel. Returning them to their communities with their families is now considered best practice."

M.: "...with family...- but we have no other family. What about another institution?"

Dr. H.: "Actually, our institution is one of the last to be closing. Funding priorities have shifted toward de-institutionalization. We feel the best option for Joseph is to place him with family."

M.: "What about those staffed homes where they all live together?"

Dr. H.: "There is always a very long waiting list for group homes or assisted living, but especially now as residential institutions are all closing or down-sizing. Our facility alone had 442 beds in its heyday. Now our last 180 are on their way out."

M.: "but Joseph, what's wrong with him – how mentally ill is he? If he's been here all this time, since he was a child – how will he cope with the outside world?"

Dr. H.: "That's why family placement is his best option..."

M.: "With me!?" But he's a complete stranger to me – and mentally ill! Would it be safe? Is he violent? I have no training to deal with this – no experience...How will I cope with this...What kind of costs would be required?"

Dr. H.: 'It will be all right. He will be on medication and have a medical supervising team to enforce his compliance with his release order. He will have to get regular blood tests to ensure he is kept on his full dose. You will find he sleeps a lot..."

Keynote Questions: "...But now we know better..."

- 1. Did you have trouble accepting this scenario as an account of something that actually happened?
- 2. What might be some of the results (negative or positive) of the large scale deinstitutionalization that took place in BC in the 90s and is happening in other countries currently today?
- 3. How could the release of patients who have previously been institutionalized be better managed?
- 4. How could families and communities be better prepared and educated?