

A Free Book for Caregivers of Individuals with Intellectual Disabilities and Mental Illness: Showcasing an Innovation

Sherri Melrose PhD, RN

Presented at the 16th Annual Canadian Collaborative Mental Health Care Conference:
Jump on the Bandwagon

June 20, 2015
Calgary, Alberta, Canada

Learning Objective

To share an innovative open access book that provides practical explanations of interest to all those who care about and for individuals with co-occurring intellectual disabilities and mental illness

..... We created a new way to deliver information to caregivers of individuals who live with both intellectual disabilities and mental illness

..... a free book that can be read or listened to online or on smartphones

This is the free book

<http://opentextbc.ca/caregivers/>

Published by BC Campus Open Education Textbook Project

Supporting Individuals with Intellectual Disabilities and Mental Illness



B.C. Open Textbook Project
open.bccampus.ca

BCcampus || OpenEd

The authors

Are a multidisciplinary team from across Canada

Professional expertise from educators in

- psychiatric nursing
- disability studies
- behavioral analysis

Practical wisdom from consultations with 20 institutions that educate and employ direct support workers

Supporting Individuals with Intellectual Disabilities and Mental Illness



B.C. Open Textbook Project
open.bccampus.ca

BCcampus || OpenEd



The cover reflects our thinking that informed support helps make the road easier to travel for those who live with both intellectual disability and mental illness

Each chapter presents current evidence informed practice knowledge. Each topic is also presented with audio enabled text boxes emphasizing 'Key Points for Caregivers.' For those who are interested in background knowledge, we provided the comprehensive literature base. And, for those interested mainly in 'what to do,' we provided text box summaries for reading and listening.

Supporting Individuals with Intellectual Disabilities and Mental Illness



B.C. Open Textbook Project
open.bccampus.ca

BCcampus || OpenEd

- Readers can dip into this book to find answers to their questions about why people with dual diagnosis might be acting in a particular way
- Educators and employers from a variety of different disciplines can share the suggestions in the 'Key Points for Caregivers' with learners, either as handouts or other teaching materials
- Busy caregivers can read about or listen to the information they need in the car between client visits or wherever and whenever they are able

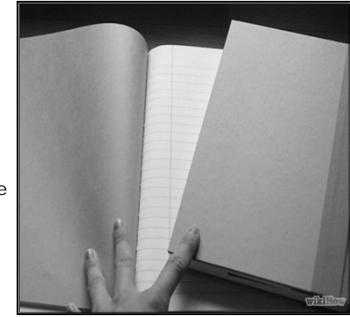
Audio Example

Here is an example of how one topic, psychosis, has been summarized in a text box and then read aloud



Creating the Book A Three Phase Process

- First - a foundational research project
 Second – disseminating the findings
 Third –knowledge translation



First - Foundational Research Project

- Year long action research project implementing a health promotion activity with individuals living with both intellectual disability and mental illness
 - Our activity used a 'WrapAround' approach to hold monthly meetings with clients to address issues before they became 'problems'
 - Included agency directors, client coordinators, direct support workers, families, employers – clients selected their own 'WrapAround' team

Second - Disseminating Our Findings

- Traditional journal publications and conference presentations ... to professionals (Eg – constant caregiver turnover heightens anxiety)
 - ...but what about front line direct support workers ???
- We also noticed caregivers had limited resources to help them recognize and respond to indicators of mental illness. One support worker believed hearing voices was part of intellectual disability – unaware of client's diagnosis of schizophrenia

Mental health nurses (RPN's & RN's) are experts in mental health issues

And yet, this expertise may not always be available to those who work with people living with a dual diagnosis

How could we capture some of this kind of knowledge in an accessible resource?



- Began with topics from Athabasca University undergraduate RN course
- Next collaborated with Debra Dusome & John Simpson, Brandon University psychiatric program
- Later invited Cheryl Crocker, Grant MacEwan University rehabilitation Studies
- Then included Elizabeth Athens, Douglas College behavioral analysis



But again – what about the direct support workers & other caregivers (employers, volunteers)
... this led to considerations about how expert knowledge could be translated to those who needed it most - caregivers

Third – Knowledge Translation

- After the multidisciplinary team of educators from across Western Canada wrote the book
..... we sent it to over fifty programs and agencies across Canada who trained or employed direct support workers for review/feedback
- We received & incorporated responses from over 20 programs
.... These 'champions' agreed to post the resource on their websites and use it in their training and orientation work

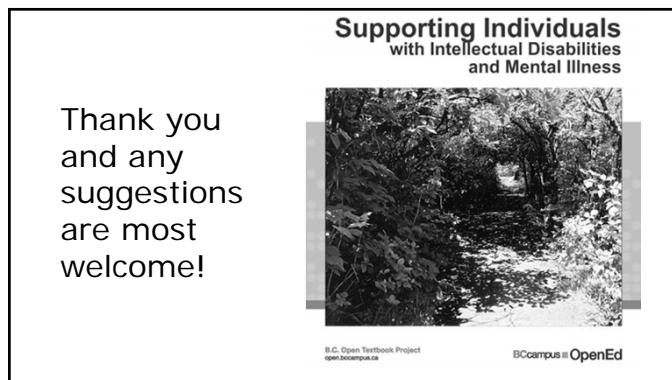
Publication with BC Campus OER Open Education Resource

- Our book/resource was awarded one of the first OER grants
....we employed a professional editor to unite our authoring voices
....& a tech consultant to create the online and Smartphone access formats

Next Steps

- Evaluate if and how the free resource is being used
- Do caregivers find the online e-book with its short summarizing text boxes and audio explanations helpful?
- Did we provide the information caregivers need in a relevant practical way?





Thank you
and any
suggestions
are most
welcome!