

Stories of Courage: Living with Co-occurring Developmental Disabilities and Mental Illness

Theme - Foster recovery and well-being for people of all ages living with mental health problems and illnesses and uphold their rights.

Presented at the
Mental Health Nursing ... A Journey of
Collaboration, Culture and Change

Canadian Federation of Mental Health Nurses Conference

October 4, 2013
Kelowna, BC Canada

Sherri Melrose PhD, RN

Athabasca Campus Athabasca Alberta



Online Programs in the Centre for Nursing & Health Studies

- ◆ Students are post licensure nurses & health care professionals across Canada
- ◆ Remain in their home communities
- ◆ Undergrad degree in nursing -BN
- ◆ Graduate degrees –MN, -MHS, -NP
- ◆ Are you or do you know someone who is an AU graduate?
....alumni all over the world....

Research Team

Multidisciplinary

◆ CASS and PASC

- ◆ 2 Calgary agencies supporting persons with developmental disabilities (PDD)

- ◆ social work, education, psychology

◆ Athabasca & University of Calgary

- ◆ nursing, spiritual care

Common Goal

How can we help/advocate?



Research Approach

◆ **Framework** - Strengths based

- ◆ How can we celebrate clients' strengths?

◆ **Design** - Action research

- ◆ Action research implements & then evaluates new ideas in practice and asks: what can we do better?

Research Approach

◆ **The New Idea (Intervention)**

- ◆ 'WrapAround' monthly health promotion team meetings in 2012
- ◆ Clients choose team members

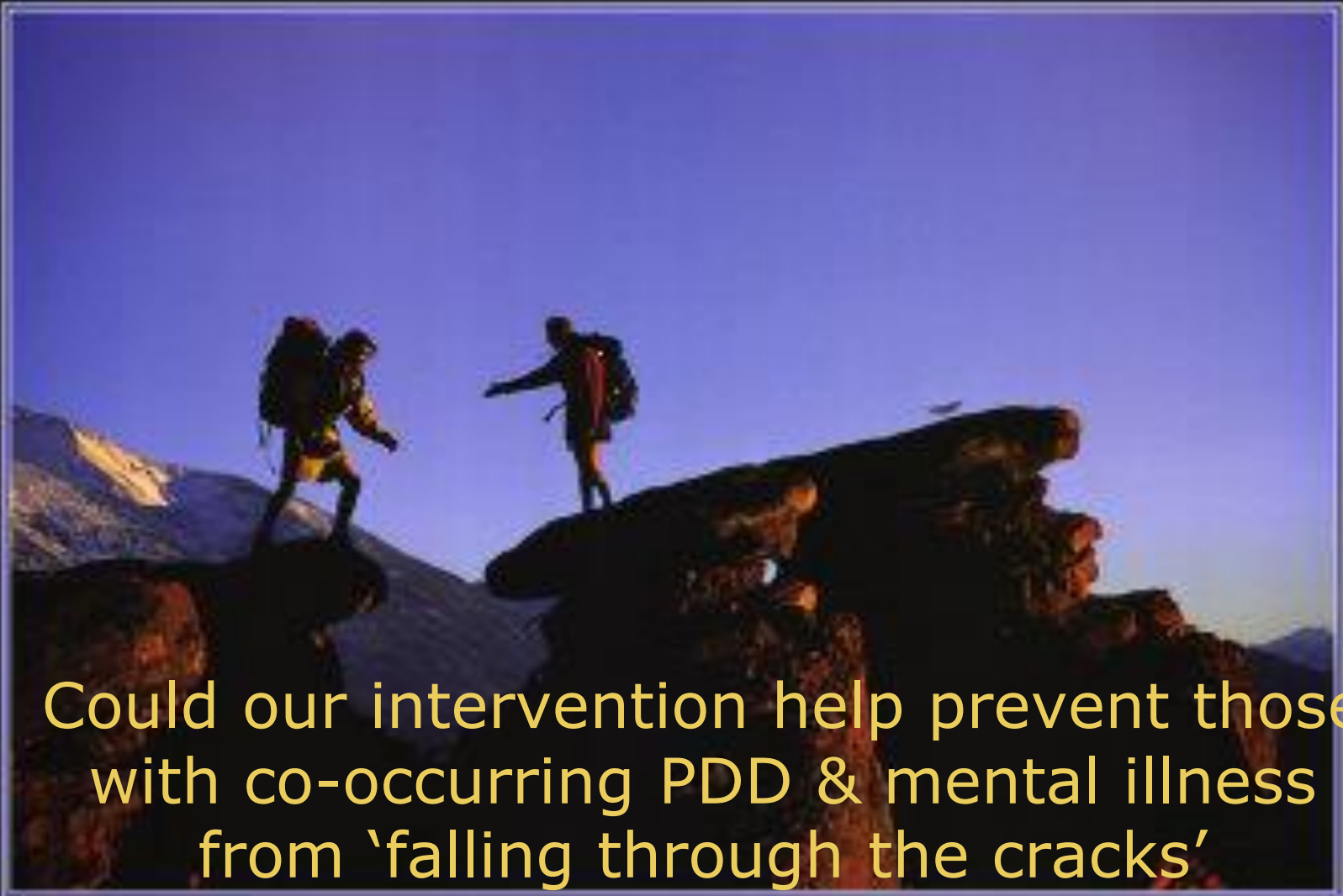
◆ **Evaluation**

- ◆ Clients & team members interviewed
 - ◆ 6 teams – 18 interviews transcribed
- ◆ Transcripts analyzed for themes

Problem

- ◆ Responding to crisis with costly ER visits & antipsychotic meds is not working
- ◆ Clients left feeling alone & isolated





ENCOURAGEMENT
Encourage others and share in the fortitude of others.

Background

- ◆ Adults with cognitive disabilities experience mental ill-health at a prevalence rate of 40.9% 3 to 4 times greater than the general population ¹
- ◆ 75% of participants with mild to moderate cognitive disabilities had all experienced at least 1 traumatic event during their life span, predisposing them to significantly increased odds of a mental disorder ²

- ◆ Hospitalized PDD adults have more severe problems & receive more interventions ^{3,4,5}
- ◆ Challenging behaviors, although not listed as DSM-5 psychiatric diagnosis, have consistently been identified as a reason for admission to hospital ^{1,6,7,8}
- ◆ Aggression, self injury & non-compliance not necessarily linked to disturbances in psychiatric functioning ^{9,10}



A Different Approach

'WrapAround' Model

- ◆ A facilitator helps clients choose a team of professionals & lay people to 'wraparound' them – regular meetings
- ◆ Previously only used with children/youth



Findings



Regular meetings where clients sought and received support from individuals they value can help address escalating symptoms of mental illness

Does a

© Jaybee 2001

Say Fenner, have we ever told you how much your support means to us?

More Findings



Constant caregiver turnover heightens client anxiety, which in turn exacerbates illness



Limited paid in-service and networking opportunities are available to caregivers

- ◆ Constant caregiver turnover impacts clients' mental health

 - ◆ 18-20 new caregivers in 3 yrs (family member interview)

 - ◆ 40% staff turnover in 1 yr (caregiver interview)

[All clinical members of the research team left]

- ◆ Caregivers paid for face-to-face time

 - ◆ Most have no pre-service training in either developmental disabilities or mental illness

 - ◆ Unable to recognize escalating symptoms

Lessons Learned

Stories of Courage

- ◆ Courage- the ability to do things which one finds frightening
 - ◆ From the French *cor* or heart
- ◆ Our clients with co-occurring PDD and mental illness showed us what the heart of courage really looks like
- ◆ A brief introduction to Ashley, Cassandra and Gord

Ashley

- ◆ Schizophrenia. 36. Lives at home with parents. Frightened by voices that parents will be hurt. Wanders at night checking. Fears knives & loud noises.
 - ◆ Caregiver of 1 yr unaware of Dx
- ◆ Created a goal chart to guide meetings
 - ◆ Family unaware of Ashley's own goals

Ashley's Goals

ASHLEY

RELATIONSHIPS

- 4 - boyfriend by 40
- marriage?

SPIRITUALITY

- has beliefs
- Karma
- angels

HOME

- learn how to do laundry (eg. sorting, using the washer amount of soap, operating the machines)
- learning to cook - using basic recipes
 - using the oven
 - using the stove
- learning to wash floors / vacuum
- once chores have been learned possibly moving in w. a roommate
- place of her own - the roommate moves in w. her
- place btwn downtown & SE
- have an apartment 1st / house or condo 2nd
- Pets - hamster / fish / dog / cat

HEALTH

- limit pop
- fitness - more time on the machines
- weight training
- 11 pm - take blue pill to help w. sleep
- 3 - get more rest
- at times her whole body feels tired
- learn to roller blade

EDUCATION

- learn Spanish

CAREER

TRANSPORTATION

- increased independence in taking the C-train & bus

Current

- work on appropriate interactions / communication (eg. not yelling from a distance)
- enforce rules to parents
- continue at Kingsland
- structure
- consistency

1.5 yr

- FT position
- a job she likes (eg. working w. children, music, movies)
- a job in a semi quiet environment
- financial independence

5 yrs

- continue on one career path & move up and grow w. the company
- gain new skills & responsibilities

Ashley's Achievements

- ◆ Employment/volunteer search shifted from childcare to office environment
 - ✦ Presentation more professional
- ◆ Coped with fear of knives through caregiver support with cooking
 - ✦ Brought baked items to neighbor
 - ✦ Reciprocity
 - ✦ Social role valorization

Cassandra

- ◆ OCD. 52. Lives with elderly Mum. Spends hours arranging hair with barrettes.
 - ◆ Overspending on barrettes & cigarettes
 - ◆ Mum experiencing failing health
- ◆ Previous abuse/trauma with boyfriend
 - ◆ Withdrew & became isolated
 - ◆ Abuse went unnoticed by family/caregivers
- ◆ Attended scrapbooking with sister

Cassandra's Creations



Cassandra's Achievements

- ◆ Plans to move with supportive roommate
 - ◆ Extensive interviewing & pre-move meetings
- ◆ Quit smoking using electric cigarettes
 - ◆ Modeling by caregiver & support from family
- ◆ Established trust with same caregiver after 5 years
 - ◆ Plan in place if she 'doesn't like' new caregivers (constant staff turnover)

Gord

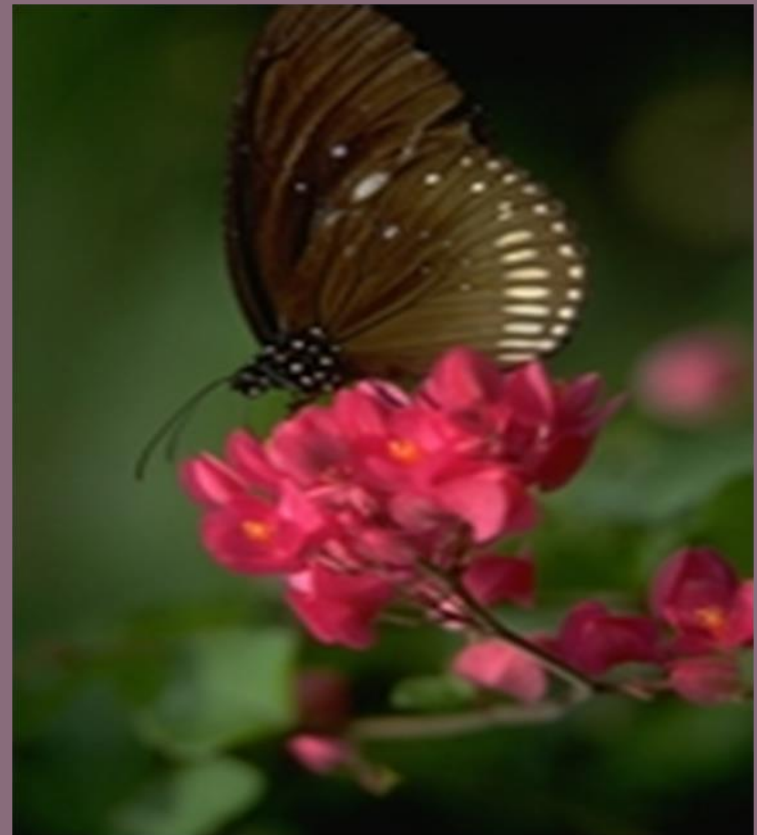
- ◆ Autism. 46 Lives in his own suite.
Trustee oversees AISH. First Nation family offers only inconsistent support
 - ◆ Family forgot to pick him up for wedding
- ◆ Overspending
 - ◆ Unpaid bills - serious consequences
- ◆ Addictions/Justice system
 - ◆ Forging cheques, fighting, 'friends'

Gord's Achievements

- ◆ Strategies in place for family demands
 - ◆ Screen calls with answering machine
- ◆ Budgeting Plans
 - ◆ Monthly installments
 - ◆ \$10.00 monthly for cable, lawyer bills
- ◆ Plan to continue monthly meetings
 - ◆ Brings 'papers' for help deciphering
 - ◆ Address literacy issues before problems develop

Working Together

- ◆ Any ideas
Resources
suggestions...
for us to help
strengthen our
research plans?





References

1. Cooper, S., Smiley, E., Morrison, J., Williamson, A., & Allen, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British Journal of Psychiatry*, 190, 27-35.
2. Martorell, A., Tsakanikos, E., Pereda, A., Gutiérrez-Recacha, P., Bouras, N., Ayuso-Mateos, J. (2009). Mental health in adults with mild and moderate intellectual disabilities: The role of recent life events and traumatic experiences across the life span. *The Journal of Nervous and Mental Disease*, 197(3), 182-186.
3. Bouras, N., Martin, G., Leese, M., Vanstraelen, M., Holt, G., Thomas, C., Hindler, C., Boardman, J. (2004). Schizophrenia-spectrum psychoses in people with and without intellectual disability. *Journal of Intellectual Disability Research*, 48, 548-55.
4. Morgan, V., Leonard, H., Bourke, J., & Jablensky, A. (2008). Intellectual disability co-occurring with schizophrenia and other psychiatric illness: Population-based study. *The British Journal of Psychiatry*, 193, 364 - 372.
5. Chaplin, R. (2011). Mental health services for people with intellectual disabilities. *Current Opinion in Psychiatry*, 24(5), 372-6.
6. Cooper, S., Smiley, E., Allan, L., Jackson, A., Finlayson, J., Mantry, D., Morrison, J. (2009). Adults with intellectual disabilities: prevalence, incidence and remission of self-injurious behaviour, and related factors. *Journal of Intellectual Disability Research*, 53(3), 200-216.
7. Cooper, S., Smiley, E., Jackson, A., Finlayson, J., Allan, L., Mantry, D., Morrison, J. (2009). Adults with intellectual disabilities: prevalence, incidence and remission of aggressive behaviour and related factors. *Journal of Intellectual Disability Research*, 53(3), 217-232.
8. Whitaker, S., & Read, S. (2006). The Prevalence of psychiatric disorders among people with intellectual disabilities: An analysis of the literature. *Journal of Applied Research in Intellectual Disability*, 19(4), 330-345
9. Allen, D. (2008). The relationship between challenging behavior and mental ill-health in people with intellectual disabilities: A review of current theories and evidence. *Journal of Intellectual disabilities*, 12(4), 267-295.
10. Allen, D. & Davis, D. (2007). Challenging behaviour and psychiatric disorder in intellectual disability. *Current Opinion in Psychiatry*, 20(5), 450-455.