Collaborative Research Grant Initiative: Mental Wellness in Seniors and Persons with Disabilities

Seed/Bridge Fund Final Report

Supporting Individuals with Developmental Disabilities and Mental Illness

April 2013 – Sherri Melrose PhD, RN
**EXECUTIVE SUMMARY**

Supporting individuals afflicted with both a developmental disability and a mental illness requires consistent and ongoing communication among clients, their family and paid caregivers. Responding to clients’ crisis solely with hospitalization and psychotropic medication is short sighted.

This year long project provides an alternative approach. Facilitators held monthly health promotion meetings where clients invited a team of family members and paid caregivers to “WrapAround” them. Discussions at the meetings focused on clients’ strengths, their goals and individualized strategies for success.

At the completion of this naturalistic action research project, data collected from interviews with clients and members of their teams was analyzed to reveal three themes.

1. Regular meetings where clients seek and receive support from individuals they value can help address escalating symptoms of mental illness.
2. Constant caregiver turnover heightens client anxiety, which in turn exacerbates illness.
3. Limited paid in-service and networking opportunities are available to caregivers.

Knowing that regular meetings with clients can address escalating symptoms of mental illness; that caregiver turnover heightens client anxiety; and that limited in-service opportunities are available to caregivers, implications for policy and practice become apparent. Clients benefit from long term, scheduled health promotion meetings; caregivers need retention incentives; and caregivers require paid opportunities to network and grow professionally.

Directions for further research include exploring ways to support clients through long term health promotion activities and ways to retain and educate their staff.

**RESEARCH OVERVIEW**

**Objective(s)**

The objectives of this project are:

1. Implement and evaluate a ‘WrapAround’ health promotion approach with individuals dually diagnosed with a developmental disability and mental illness.
2. Identify barriers to supporting dually diagnosed individuals.

**Background**

**Problem Description:** Persons with developmental disabilities (PDD) experience mental illness at a prevalence rate of 40.9%, 3 to 4 times greater than the general population (Cooper, Smiley, Morrison, Williamson, & Allen, 2007). When admitted to psychiatric units, their problems can be more severe and they can receive more interventions than individuals without developmental disabilities (Chaplin, 2011). They may spend more days in hospital (Bouras, Martin, Leese, Vanstraelen, Holt et al, 2004; Morgan et al, 2008; Saeed, Ouellette-Kuntz, Stuart & Burge, 2003). The majority are likely to be subjected to chemical restraint (Webber, McVilIl & Chan, 2011).

In Canada estimates suggest that 380,000 Canadians (Yu & Atkinson 1993, republished in 2006) and between 6,000 and 13,000 Albertans live with a dual diagnosis (Hughson, 2009). About 42% of all hospitalizations among PDD Canadians occurred for psychiatric conditions (Lunskey & Balogh, 2010). Canadians with PDD are at 15 times higher risk of receiving a psychiatric admission of schizophrenia (Balogh, Brownell, Ouellette-Kuntz et al., 2010) and this risk is also 3 to 4 times greater than the general population (Morgan, Leonard, Bourke & Jablensky, 2008). Further, PDD Canadians are at 4
to 5 times higher risk of experiencing dementia and at nearly 3 times higher risk of being depressed than non PDD individuals (Shooshtari, Martens, Burchill, et al. 2011). 14% of PDD participants in an Australian study had an incapacitating anxiety disorder (White, Chant, Edwards, Townsend, Waghorn, 2005). Clearly, high rates of psychiatric unit admissions are occurring among this population. Responding to PDD clients’ psychiatric conditions solely with hospitalization and psychotropic medication is short sighted.

**Importance of Addressing the Problem:** Despite the high prevalence of mental illness in the PDD population, limited support and services are available to these individuals, their families and their paid caregivers. In a national survey examining the range of mental health services available to individuals with a dual diagnosis and perceived service gaps across Canada, respondents identified that generic mental health providers were poorly equipped to meet the needs of these individuals, that waitlists for specialized services were typically 4 months or longer and less than half of the respondents reported that expertise or specialized services existed in inpatient treatment or emergency room facilities (Lunsky, Garin, Morin, Cobigo, & Bradley, 2007).

An inability to access appropriate mental health services in a timely manner leads to crises resulting in hospital emergency room visits, warranting intervention to correct the deficiencies at both the clinical and systems levels (Lunsky, Gracey, & Gelfand, 2008). Alternative approaches focused on promoting wellness and addressing escalating symptoms of mental illness are urgently needed.

**Approach and Methods**

This project was framed from a strengths based conceptual perspective (Rapp, Saleebey & Sullivan, 2005; Saleebey, 2006) and a naturalistic action research design (Kemmis & McTaggart, 1990). Action research implements and then evaluates new ideas in practice and asks the question “what can we do better?” (Kiener & Koch, 2009). Our research posed the question: What can we do better to prepare PDD clients to anticipate and prevent a psychiatric mental health crisis before hospitalization occurs. Participants were recruited from two Calgary agencies serving PDD clients. Ethical approval was obtained from Athabasca University.

Modeling the action research intervention on a ‘WrapAround’ approach, facilitators provided monthly health promotion meetings to six PDD clients at risk of experiencing a psychiatric mental health crisis. Individually, each client was helped to create a team of family members and paid caregivers to "wrap around" them. Throughout 2012, the six teams met regularly and facilitators guided discussions to focus on clients’ strengths, their goals and individualized strategies for success.

The WrapAround approach is an intensive, holistic method of engaging with individuals with complex needs so that they can live in their homes and communities and realize their hopes and dreams (National WrapAround Initiative, n.d.). The approach is a client driven, team oriented planning model. Typically used with children, youth and their families, this project is unique in adapting the model to PDD clients. The approach espouses:

“a philosophy of care beginning from the principle of 'voice and choice,' which stipulates that the perspectives of the family—including the [client]—must be given primary importance during all phases and activities of wraparound. The values associated with WrapAround further require that the planning process itself, as well as the services and supports provided, should be individualized, family driven, culturally competent, and community based. Additionally, the WrapAround process should increase the 'natural support' available to a family by strengthening interpersonal relationships and utilizing other resources that are available in the family's network of social and community relationships. Finally, the WrapAround process should be 'strengths based,' including activities that purposefully help the [client] and family to recognize, utilize, and build talents, assets, and positive capacities” (National WrapAround Initiative, n.d. ¶3).

Facilitators closed the project by reviewing the efficacy of the intervention (the WrapAround team approach) and exploring barriers that participants experienced. Each client and at least one member of their WrapAround teams were interviewed by a researcher not involved with their teams or with the
agency providing their care. Transcripts of the interviews were used as data sources. The interview transcripts were analyzed using line by line coding to create categorizations that led to themes. QRS International’s NVivo 10 was used to organize the data collection and analysis. Trustworthiness was established by member checking with the participants to ensure authenticity.

**Key Findings**

Three themes emerged from discussions with both PDD clients who are at risk of experiencing a mental health crisis; and the family members and/or paid caregivers on their Wrap Around teams.

1. Regular meetings where clients seek and receive support from individuals they value can help address escalating symptoms of mental illness.
2. Constant caregiver turnover heightens client anxiety, which in turn exacerbates illness.
3. Limited paid in-service and networking opportunities are available to caregivers.

This action research project illustrated a health promotion approach that participants found helpful. The project provided participants with monthly meetings where support teams ‘wrapped around’ clients and supported them towards success. Rather than responding to clients in crisis, the monthly meetings created opportunities for family and paid caregivers to support well clients. The regular meetings created opportunities to address clients’ escalating symptoms of mental illness when they first appeared, thus preventing costly hospitalizations.

Discussions with clients and their WrapAround team members revealed the impact that constant caregiver turnover has on clients’ health. One caregiver identified a 40% yearly staff turnover in her program. A family member explained how adjusting to 18 to 20 new caregivers in a three year period heightened her loved one’s anxiety. Clients, family members and caregivers all agreed that this anxiety in turn exacerbated illness.

Most caregivers interviewed in this project noted that they are paid only for face to face time with clients. Therefore, professional development opportunities such as in-services, workshops and networking opportunities with colleagues and other professionals are not available to them. Several had no pre-service education and/or training in either developmental disabilities or mental illness. They expressed that recognizing escalating symptoms of mental illness was challenging and indicated their willingness to learn more.

A summary of participants’ goal progression and barriers is presented in Table 1.

<table>
<thead>
<tr>
<th>(Pseudo)Name</th>
<th>Goal Progression</th>
<th>Barriers</th>
</tr>
</thead>
</table>
| Cassandra    | -moving from elderly Mum’s home to live with a supportive roommate  
-quit smoking (electric cigarettes)  
dental cleanings without freezing  
-trusting relationship with support worker after 5 years  
-joined sister at scrapbooking  
See Appendix A for a collage created to celebrate Cassandra’s strengths | -constant staff turnover heightens anxiety. Not sure if she will ‘like’ new caregivers. Obsessive behaviors increase when new staff assigned |
| Ashley       | -employment/volunteer search shifted from childcare to office environment  
-less calling in sick for programs  
-more consistent attendance at gym  
coped with fear of knives through caregiver support with cooking  
See Appendix B for a goal chart created to guide Ashley’s meetings | -limited understanding of mental illness decreased early recognition of escalating symptoms of schizophrenia: e.g.: hearing voices  
-weight gain a medication side effect |
<table>
<thead>
<tr>
<th>(Pseudo)Name</th>
<th>Goal Progression</th>
<th>Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gord</td>
<td>-debt repayment plan in place&lt;br&gt;-recognizing addiction triggers more</td>
<td>-impaired social interaction associated with autism makes employment overwhelming</td>
</tr>
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<td>Garry</td>
<td>-anger management strategies helping to decrease outbursts of rage&lt;br&gt;-created resume for part time work</td>
<td>-limited understanding of mental illness decreased early recognition of escalating symptoms of autism, leading to police involvement&lt;br&gt;-few opportunities for supportive roommate to network with peers and learn more about mental illness</td>
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<td>Kurt</td>
<td>-strategies in place to promote hygiene, e.g.: mirror and wastebasket&lt;br&gt;-seeking opportunities to make friends&lt;br&gt;-arriving at program on time more consistently</td>
<td>-limited understanding of mental illness decreased early recognition of escalating symptoms of schizophrenia: e.g.: withdrawal&lt;br&gt;-expectations of existing friendship programs geared to the mentally ill considered too high</td>
</tr>
<tr>
<td>Will</td>
<td>-despite declining to continue with WrapAround, achieved success by risking trying a new activity</td>
<td>-constant staff turnover heightens anxiety. Reluctant to engage in new activities when staff continually ‘leave’</td>
</tr>
</tbody>
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**Conclusions**

Clients benefit from long term, scheduled health promotion meetings; caregivers need retention incentives; and caregivers require paid opportunities to network and grow professionally. Resources to help paid caregivers understand how to best support individuals dually diagnosed with developmental disability and mental illness are needed.

**Implications for Policy or Practice**

This action research project is one example of a health promotion intervention implemented by the front line caregivers who work with developmentally disabled individuals. As findings from this project illustrated, an approach where well clients meet regularly with family and caregivers to discuss clients’ strengths, goals and strategies for success was helpful. Implementing similar meetings, centering on mental health promotion could become common practice. Policies and practices that invite caregivers to initiate other health promotion activities, particularly in the area of mental illness must be initiated. Further, a critical review of funding models that pay caregivers only for face to face time with clients must also be initiated.

**Directions for Further Research**

Given the high prevalence rate of mental illness among persons with developmental disabilities, further research in the area of health promotion is needed to determine approaches that provide clients with the long term support they need. In the area of educational research, the creation of practical, relevant and accessible resources explaining escalating symptoms of mental illness should be explored. Questions related to the high staff turnover in this field must continue to be asked.

**Knowledge Dissemination and Translation Activities**

The multidisciplinary research team included members from nursing, social work, education, psychology and spiritual care. Members have initiated dissemination activities in different professional venues, for example, conference presentations. The research group plans to continue meeting to develop manuscripts for publication consideration. Several of the WrapAround teams also plan to continue meeting and these meetings may lead to additional dissemination activities. The executive summary of the project was provided to all participants and agency staff who expressed interest.

**Principal Applicant (Team Leader)**
Dr. Sherri Melrose  
Associate Professor, Athabasca University  
Psychiatric nursing

**PROJECT PARTNERS (TEAM MEMBERS)**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position Title</th>
<th>Role</th>
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<tr>
<td>Carol Urness</td>
<td>Executive Director, Calgary Alternative Support Services (CASS)</td>
<td>Advise members of the research group on Wraparound process, maintain ongoing communication with Wraparound Facilitator. Receive progress reports on any CASS clients as necessary. Seek further help for participants as necessary. Attend any Wraparound Team meetings if invited by participants.</td>
</tr>
<tr>
<td>Bill Forman</td>
<td>Executive Director, Progressive Alternative Supports of Calgary (PASC)</td>
<td>As above</td>
</tr>
<tr>
<td>Dr. Paul Wishart</td>
<td>Research Consultant</td>
<td>Provide guidance on generating grounded theory</td>
</tr>
<tr>
<td>Meghan Holub</td>
<td>Resource Coordinator, Progressive Alternative Supports of Calgary (PASC)</td>
<td>Facilitate WrapAround teams</td>
</tr>
<tr>
<td>Allison Denoudsten</td>
<td>Resource Coordinator, Calgary Alternative Support Services (CASS)</td>
<td>Facilitate WrapAround teams</td>
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**PUBLICATIONS AND PRESENTATIONS**


ABOUT THE ALBERTA ADDICTION AND MENTAL HEALTH RESEARCH PARTNERSHIP PROGRAM

The Alberta Addiction and Mental Health Research Partnership Program is comprised of a broad-based multi-sectoral group, representing service providers, academic researchers, policy-makers and consumer groups, working together to improve the coordination and implementation of practice-based addiction and mental health research in Alberta.

The mission of the Research Partnership Program is to improve addiction and mental health outcomes for Albertans along identified research priority themes, by generating evidence and expediting its transfer into addiction and mental health promotion, prevention of mental illness, and innovative service delivery.

The Research Partnership Program sets out to increase Alberta’s excellence and output of addiction and mental health research findings, and to better translate of these findings into practice improvements.
REFERENCES


NVivo qualitative data analysis software; QRS International Pty Ltd. Version 10, 2013.


APPENDIX A:
SCRAPBOOKING COLLAGE CASSANDRA’S TEAM CREATED TO CELEBRATE HER STRENGTHS
APPENDIX B:
GOAL CHART ASHLEY’S TEAM CREATED TO GUIDE MONTHLY MEETINGS

Ashley’s Goals

RELATIONSHIPS
- boyfriend by 40
- marriage?

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

CAREER
- work an appropriate interaction/communication (e.g., not yelling from a distance)
- enforce rules to parents
- continue at Kingsland

TRANSPORTATION
- increased independence in taking the C-train & bus

EDUCATION
- learn Spanish

SPIRITUALITY
- has beliefs
- karma
- angels

HOME
- learn how to do laundry (e.g., 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 downtown & SE
- have an apartment 1st floor house or condo 2nd floor
- pets - hamster, fish, dog, cat

1YR
- FT position
- a job she likes (e.g., working w/ children, music, movies)
- a job in a semi quiet environment
- financial independence

5YR
- continue on one career path & move up and grow w/ the company
- gain new skills & responsibilities