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

Operating Grant Final Report

Examining the Transitional Needs of Adults with a Developmental Disability and Mental Illness

February 28, 2014 - David Nicholas
This study examined the mental health and care needs of individuals with a dual diagnosis of a developmental disability and a mental illness (DDMI) that have transitioned from inpatient care to community living within the last two years. The study explored several key areas: system capacity relative to current need; challenges that persons with DDMI encounter as they navigate the transition from institutional to community care and vice versa; the strengths that currently exist in these transitions; and perceived needs to enhance access and coordination of mental health and developmental disability services.

A total of 95 individuals participated in this study, including service providers from across the 5 regions (Edmonton, Red Deer, Peace River, High Level and Grande Prairie) who participated in semi-structured focus groups, and individuals with DDMI or their family/informal caregivers who participated in individual interviews.

Findings identified several important areas. For instance, service provision was described as complicated: service providers juggle the quality of their work with the demands of their caseload; the segregation and multiplicity of systems in which individuals work can impose barriers to optimal and seamless service provision; cultural variation and ESL present challenges and opportunities for development; in smaller communities, individuals are required to travel to access specialized mental health or related health services; the lack of community-based service has reportedly increased utilization of emergency services as a first line response; resources are accessed based on a diagnosis as opposed to a ‘fit to functioning’ approach; and staffing levels and retention are barriers to care in the community.

While community based services and residential living were preferred by both individuals and care providers, services are needed to maintain care sufficiency and individual stability in the community. Often, individuals’ needs were thought to be too great for homecare providers, requiring individuals, in some cases, to access an acute care setting, sometimes in a distant urban centre. In cases where parents or guardians were unable to provide care, individuals were forced to remain in hospital until a new placement was found. Due to limited spaces available, individuals often experienced extended delays and challenges in finding adequate housing and care. The lack of fit among residents was also thought to often compromise the ability to maintain health and mental health stability within the community.

Individuals receiving services were described to often lack sufficient social and vocational opportunity and engagement. As service providers and care homes were often unable to facilitate individuals within community settings, these individuals experienced increased dependence upon families (e.g., parents and guardians) for meaningful interaction and community participation. This often caused substantial stress for families, as individuals were dependent upon care providers for transportation, advocacy, finances, and in some cases, housing. Unfortunately dependence upon the family was, at times, cause for increased individual and family isolation and tension within familial relationships.

The study identified difficulties associated with community and transitional care, and a generalized lack of understanding about the complex needs of adults with DDMI. Participants reported concern about the lack of individualized care planning and provision, and suggested that individuals with DDMI can become more reactionary and in some cases, frustrated or agitated, when unengaged. Participants believed that individualized care management in conjunction with increased services, would assist in maintaining individuals within their community due to their ability to better facilitate individuals in a customized, sustained ‘program’ of support including meaningful community participation. Findings invite a seamless
approach between institutional and community care, with a focus on specialized community care for individuals with DDMI.

**EXECUTIVE SUMMARY**

Up to 80% of the estimated 3,500 Albertans who spend at least one day per year in inpatient psychiatric institutions have a dual diagnosis of mental illness and either a cognitive or physical disorder. Of these, a substantial proportion also have a developmental disability. These dually diagnosed individuals (developmental disability and mental illness [DDMI]) have complex care needs, and arguably are among the most physically and socially vulnerable in our communities. Effective transition from inpatient to community care (and vice versa) rests on the sufficiency of supports and services addressing the care needs of this population, and community capacity to address specific individual-based needs within the compendium of available mental health and developmental disability resources. This study examined the transitional and community care needs of dually diagnosed adults in five communities in central and northern Alberta. Through focus groups with service providers and interviews with dually diagnosed individuals and their families/informal caregivers, the study elicited transitional challenges, community-based support and service needs, and perceived means for effective transitional and community care. The study identified challenges and recommendations.

**RESEARCH OVERVIEW**

**Objectives**

To address experiences associated with transitional services, this study examined the mental health and care needs of individuals with a dual diagnosis of DDMI who have transitioned from inpatient care to community living within the last two years. Research questions were as follows.

1. What are the experiences of adults with dual diagnoses who are transitioning from inpatient care to community living?
2. From the perspectives of adults with dual diagnoses, family caregivers and service providers, what resources are required to facilitate an effective transition to the community?
3. To what extent do service providers feel prepared to meet the needs of adults with dual diagnoses transitioning into the community?
4. What supports are required to enable individuals with severe challenging behaviours to remain in the community?
5. What additional resources are required by service providers to meet these needs?

**Background**

The *Persons with Developmental Disabilities Community Governance Act* defines developmental disability as a significant limitation in both adaptive skills and intellectual capacity that begins in childhood (Government of Alberta, 1995). To be diagnosed with a developmental disability, onset must occur prior to 18 years of age, and the individual must have significantly below average intelligence and substantial limitations in two or more adaptive skill areas, such as communication, self-care, work, and home living (Government of Alberta, 1995). According to Health Canada (2002), a mental illness is “characterized by alterations in thinking, mood or behaviour (or some combination thereof) associated with significant distress and impaired functioning over an extended period of time” (p. 16). Some examples include depression, anxiety, schizophrenia, and personality disorders (Health Canada, 2002). Individuals dually diagnosed with DDMI often contend with further medical conditions such as epilepsy that exacerbate their difficulties (Davis, Barnhill, & Saeed, 2008). It is clear that dually diagnosed individuals have complex needs, making them among the most vulnerable in our community (Alberta Mental Health Board, 2002; Bongiorno, 1996; Davis et al., 2008).

Individuals with dual diagnoses require specialized, intensive, long-term treatment involving considerable attention and effort from an interdisciplinary team of psychologists, psychiatrists, social workers, nurses, doctors, occupational therapists, dieticians, etc. (Bongiorno, 1996; Davis et al., 2008; Torrey, 1993). Although many individuals live in the community, research has consistently

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1 For the purposes of this study, the term “dual diagnosis” will refer to adults who have both a developmental disability and one or more mental illnesses (Alberta Mental Health Board, 2002).
shown that inpatient treatment is required for those with severe dual diagnoses given their complex care needs (Hackerman, Schmidt Jr., Dyson, Hovermale, & Gallucci, 2006). Although long-term hospitalization is necessary for the most severe cases, many adults with dual diagnoses require periodic inpatient psychiatric care, and are discharged once deemed to be stabilized. However, of those who are hospitalized in a psychiatric facility, nearly half are readmitted within 180 days of discharge, and of these 88% are readmitted within two years of their second discharge (Shoham-Vardi et al., 1996). The hospitalization rates of people with dual diagnoses are unknown. Among Alberta’s general adult population, approximately 3.7% access psychiatric services annually and 3,436 individuals spend at least one day as a psychiatric inpatient (Alberta Mental Health Board, 2007). Given that dually diagnosed individuals present complex care challenges, it is reasonable to assume that these individuals make up a relatively large proportion of the number of people who require inpatient treatment annually.

**Resource Capacity**

The increasing rate at which inpatients are being discharged from institutions into the community has particular implications for the treatment of individuals with dual diagnoses (Davis et al., 2008; Torrey, 1993; Woodward, 1993). Considering the complex interdisciplinary programs needed, community service delivery must be well-coordinated and have necessary supports in place for caregivers, including the availability of acute inpatient services when required (Davis et al., 2008; Fotheringham, 1999; Hackerman et al., 2006; Woodward, 1993). Essential in facilitating this process is strong advocacy and case management for adults with dual diagnoses (Davis et al., 2008). Unfortunately, community support services are often not readily available, and resources tailored to address the complex needs of this special population are especially lacking (Davis et al., 2008; Fotheringham, 1999; Torrey, 1993). Even where community resources are available, divergent treatment models and philosophies may prevent effective collaboration and interrupt continuity of care (Davis et al., 2008; Hackerman et al., 2006; Woodward, 1993). These are significant issues due to the overwhelming challenges these individuals and their caregivers face (Davis et al., 2008).

**Key Elements of Successful Transition**

The successful transition of individuals with dual diagnoses to community care requires a number of supports. Transitioning individuals from institutions to community-based living requires expertise from a number of disciplines, which means that community care must be well-integrated and coordinated (Davis et al., 2008; Fotheringham, 1999; Hackerman et al., 2006; Woodward, 1993). To ensure that such care is available, community service providers must have consistent treatment models and philosophies (Davis et al., 2008; Hackerman et al., 2006; Woodward, 1993). When navigating the community care system, individuals with dual diagnoses also require strong advocates and case managers to establish effective treatment programs. In addition, it is helpful if treatment programs are individualized to account for the diverse needs of this group. This individual approach includes a person centered-focus and flexibility in treatment programs. Service providers must have access to treatment and financial resources that they need to provide sound interdisciplinary care (Davis et al., 2008).

**Approach**

A mixed method design was integrated including qualitative interviews with adults with dual diagnoses and family caregivers examining experiences and needs in transitioning from inpatient care to community living. Participants were initially informed of the study by a familiar service provider. If interested in further information about the study, the service provider obtained consent from the participant and his or her legal guardian to release their names and contact information to the research team. They were then contacted by a research team member who explained the purpose and procedures of the study and inquired about potential interest in study participation. Potential participants were informed that their participation was entirely optional, and written consent was obtained from individuals interested in participating in the study. Institutional research ethics board review and approval was received prior to study commencement.
Data Collection

*Phase 1: Qualitative Interviews:* Individuals with dual diagnoses and their family caregivers participated in individual semi-structured interviews. Interviews addressed each of the research questions using McCracken's *long interview method* (McCracken, 1988). This approach invited open expression of participants' perceptions while ensuring thorough coverage of common topical areas across the sample of interviewees.

*Phase 2: Focus Groups with Service Providers:* Community and inpatient service providers were invited to participate in focus groups (approximately 5 to 7 participants per group). Community service providers were recruited across relevant sectors including mental health, medical, housing, justice, vocational, and financial services. In focus groups, participants were invited to reflect on: (i) needs and strengths within existing service systems, (ii) the current availability of resources for this population, and (iii) means by which relevant systems in the region and the province as a whole could improve transitional services and meet the needs of adults with dual diagnoses.

*Phase 3: Delphi Consultation:* Following the analysis of interview and focus group data, Delphi consultations were held with key stakeholders and practice and policy development leaders. The Delphi contained an ‘expert’ panel of individuals comprising providers of inpatient care to adults with dual diagnoses who have been readmitted from the community, and policy and practice leaders involved in community care. The Delphi consultation is ideal in advancing descriptive and thematic findings to a set of guidelines to be applied in relevant clinical situations, and in the development of an integrated set of policy or practice statements and recommendations.

Deliverables from this approach to data collection included key elements related to the transition to the community (from institutional care) for individuals with dual diagnoses, considerations for transition planning, key characteristics of transitions from inpatient to community care, priorities for transition-based tools, and implications for programming and practice.

Data Analysis

Interviews, focus groups and the Delphi consultation process were digitally recorded and transcribed verbatim, with the exception of all potentially identifying information which was removed from transcripts. Transcripts were analyzed for themes using qualitative analysis computer software (NVivo8). McCracken’s comprehensive data analysis procedures were used, comprising: (i) line-by-line coding of the data, (ii) examination of the interconnection of emerging codes within the data, and (iii) identification of emergent patterns and themes (McCracken, 1988). Rigor (trustworthiness and authenticity) of qualitative findings was ensured, thereby offering increased assurance of methodological diligence and confidence in emergent findings.

The Sample

A total of 95 individuals participated in this study, including service providers from across the 5 regions involved in this study (Edmonton, Red Deer, Peace River, High Level, and Grande Prairie). Service providers participated in semi-structured focus groups, and individuals with DDMI or their family/informal caregivers participated in individual interviews.

Key Findings

Participants predominantly identified difficulties associated with community-based care, and a general lack of understanding about the unique needs associated with persons with DDMI transitioning between community and institutional care. Service provision to adults with DDMI was described as complicated including the following challenges.

- Service providers juggled the quality of their work with the demands of their caseload.
- The segregation and multiplicity of systems in which individuals with DDMI and families navigate and service providers work, can impose barriers to optimal and seamless service provision.
- Linguistic variation can present communication challenges.
- In smaller communities, individuals are required to travel to access medical or mental health services with limited local clinical availability of services.
The lack of community-based service appears to impact utilization of emergency services as a first line response.

Community agency staffing levels and retention issues are barriers to care and capacity building in the community.

Resources are often administered on the basis of a diagnosis as opposed to a ‘fit to functioning’ approach.

While community-based services and residential living were preferred by both individuals and care providers, enhanced services and coordination are needed to maintain care sufficiency and individual stability in the community. The needs of individuals with DDMI were thought to periodically exceed that offered by homecare providers – requiring individuals with DDMI and their families, in some cases, to access an acute care settings sometimes in a distant regional centre. In cases where parents or guardians were unable to provide care, individuals were forced to remain in hospital until a new placement was found. Due to limited spaces available, individuals often experienced extended delays finding adequate housing and care. Exacerbated behaviours seen by home-based care providers were sometimes thought to be amplified by employees’ lack of knowledge about the specialized needs of individuals with DDMI and/or a lack of best practices with this population. Further, the lack of an ideal ‘fit’ of services relative to the needs of persons with DDMI was thought to often compromise their stability of health and mental health within the community.

Beyond clinical services, individuals receiving services were described to often lack sufficient social and vocational opportunity and engagement. If service providers and care home settings were unable to facilitate individuals within the community, these individuals with DDMI were at greater risk for dependence on families (e.g., parents and guardians) for meaningful community participation. This often caused substantial stress for families, as individuals were dependent upon family care providers for transportation, advocacy, finances, and in some cases, housing. Unfortunately dependence upon the family was, at times, cause for increased individual and family isolation and tension within familial relationships.

Along with a lack of services and programs related to community-based care, participants reported concern about a lack of individualized care planning and provision. Participants suggested that individuals with mental illness can become more reactionary and in some cases, frustrated or agitated, when unengaged. Participants believed that individualized care management in conjunction with increased services, would assist in maintaining individuals within their community due to their ability to better facilitate individuals in a customized, sustained ‘program’ of support including meaningful community participation.

Participants identified multiple challenges at a resource level, as follows.

**Crisis Orientation in Care:** Several periodic service providers described working in a “continual crisis orientation” whereby they evaluate and reactively respond to crises. One service provider stated, “We’re busy band-aiding a lot of stuff.”

**Shifts in Care:** With system and funding changes, service providers and recipients described a periodic need to relearn previously familiar systems of care provision.

**Work Overload:** Caseloads were reported to be overwhelming in some areas of practice and regions. Service providers described juggling the quality versus the quantity of their work. Demands for developing work plans, traveling, and navigating systems of care were identified examples of barriers to efficient caseload management.

**Extensive Travel:** Rural service providers reported extensive time traveling to outlying communities, thereby limiting overall clinical care availability. Travel was seen as a substantial expense for their agencies.
Lack of Adult Mental Health and Developmental Disability Services: If diagnosed before the age of 18 years, families may have accessed a range of pediatric programs. However, when moving into adulthood or if an individual is diagnosed as an adult, funding and programming opportunities reportedly diminish substantially after age 18.

Different Languages/Insufficient Education: Clients may not speak English or have speech language challenges; hence, may need different linguistic resources (e.g., an interpreter) that may or may not be available. Caregivers may lack English language competency which can impede communication with clients and families. Overall, there is a reported lack of staff education and professional development opportunity that in turn inhibits understanding about the complex needs of dually-diagnosed individuals.

Recruitment and Retention Challenges: Staff frequently leave or shift positions, exacerbated by higher/comparable remuneration and employment opportunities in other sectors or agencies. Given these changes, families can lose touch with who to contact when help is required, and staff capacity and professional development again are impeded.

Lack of Accessible Services in Rural and Remote Regions: Clients in smaller communities necessarily travel to access medical or mental health services. Without a diagnosis, service access is particularly limited, but obtaining an assessment for a diagnosis may require substantial cost and travel particularly for rural dwellers. Concerns were identified such as: funding inadequacy and regional service unavailability.

Inconsistent or Insufficient Funding: Targeted programming is sometimes funded only for a limited period of time. Once those dollars are expended, programs sometimes end, even if the program is deemed effective.

Service Mandate Rigidity: Service or funder mandates often require that clientele specifically ‘fit’ program categories in order to qualify for services (e.g., only emergent cases). Individuals with a dual diagnosis necessarily may cross eligibility lines, precluding access to needed programs based on eligibility criteria restrictions. Accordingly, governing bodies sometimes have mandates that exclude this population of individuals with multiple needs (e.g., developmental disability and mental illness). Funding structures were described as sometimes causing difficulty to access care, particularly if funding is needed from multiple sources/payers.

Ingenuity and Resilience: Despite barriers, examples of commitment and community ingenuity were described whereby service providers and family members worked to develop and implement plans fostering transitional navigation and community integration, sometimes by circumventing system limitations.

Findings identify multiple factors that appear to have a bearing on the experiences and outcomes for individuals with DDMI and their families. Findings entail a range of practice and policy issues and levels that differentially affect and reflect: (i) the individual and family, (ii) the context in which services are delivered and accessed, and (iii) the broader level of social discourse and policy related to adults with DDMI. The concentric circles in the emerging model (Figure 1) represent different layers that appear to have an impact on individuals with a dual diagnosis, and their families.

Included at the outer level is a prevailing social discourse which comprises elements of stigma, social attitudes, policy and other discursive considerations that reflect, foster and resist elements of societal inclusion/non-inclusion, community responses and varying social determinants of health-related solutions. At the contextual level (the next concentric layer in the model), salient factors influencing community-level experiences and outcomes appear to include: care sufficiency/insufficiency and regional resources or lack thereof to address the extent of care needs of persons with DDMI. Lastly, the internal concentric layer envelopes individual- and family-level constructs: various services involved, informal supports, family considerations, transitional processes and specific case-based resources in the community/communities involved. These elements influence the immediate experiences and outcomes for individuals with DDMI and their families.
The various elements of the emerging model appear to be inter-related relative to understanding overall transitional experience and outcome. For example, a lack of direct clinical institutional resources may lead to a poor transitional experience for the individual as do issues of stigmatization and societal attitudes related to care and service needs for persons with DDMI. Given that elements of the model are closely linked, it is important to discover ways in which we can redress issues at each level in ultimately mediating service gaps and conversely facilitating proactive transition processes from inpatient care into the community (and vice versa) as needed.

Figure 1: Individual, Context, and Social Discourse-related Features of DDMI Experience and Outcome

Parents heartily expressed the need for general support and care navigation for their adult children with a dual diagnosis. Ongoing information and support for parents was also recommended, as were professional education and community resource development.

At the contextual level, recommendations emerging from the study involved addressing gaps, as noted, including resources directed to ancillary yet integrally important needs such as access to transportation, employment, employment support and other needed resources. Considering the broad base of supports is an important consideration in optimizing community adjustment and stability for persons with DDMI. For instance, a lack of transportation for those with a dual diagnosis potentially prevents them from being able to access services, be employed and make appointments. Findings again invite a seamless approach between institution and community care and across sectors, with a focus on specialized community care and access to associated services that foster stability and growth in community living.

Conclusions
Findings identify substantial barriers faced by adults with DDMI as they navigate transitions between institutional and community care. These findings invite community-mediated considerations for determining strategies, yet also a strong, centralized resource and monitoring resource to ensure sufficiency of services, system capacity and evaluation for continual improvement. Holistic person-
and family-centred care in policy and practice is recommended. Community capacity resources fostering greater staff development and service access for individuals and families are recommended.

**IMPLICATIONS FOR POLICY & PRACTICE**

These findings inform policy-makers and decision-makers, service providers, and practitioners about system and program gaps, service needs and potential mediation strategies for improving care capacity. Building capacity in communities emerges from these findings as a priority, with unique issues for rural and remote communities and other areas of this population (e.g., individuals with DDMI who present with behavioral issues that are currently not well supported in the community). Engagement and integration are recommended across boundaries of institutional and community care as well as between ‘silos’ of human services, health/mental health and other sectors of community and civic planning (e.g., housing, vocation, advanced education, transportation, family services, industry, urban design, etc.). Greater infrastructure and resource development as well as communication systems are needed among practice communities in developing treatment, discharge and viable, sustainable care plans that are feasible and proactive within given community contexts. Cross-ministerial discussion and innovation are encouraging (e.g., CRGI and other recent cross-ministerial initiatives), and such ingenuity is strongly supported by these findings. These considerations have a substantial bearing on practice and policy development in terms of the organization, planning and implementation of services. Finally, the development of rigorous evaluation, using commonly understood and meaningful metrics at an institutional and community level, are recommended in ensuring ongoing continuous program evaluation and development.

**DIRECTIONS FOR FUTURE RESEARCH**

This study has offered guidance in designing a follow-up study including a planned knowledge translation study and an intervention trial evaluating an educational and transitional support intervention for individuals with DDMI and their families as well as for local service providers. The development of a ‘toolkit’ for regional programs and service providers is planned and educational resources for individuals and families are underway. These endeavors and projects will contribute to project impact, but will also offer foundation development for further research development based on findings from this study.

**KNOWLEDGE DISSEMINATION AND TRANSLATION ACTIVITIES**

We have already presented this research and are planning additional knowledge dissemination and translation activities for increased findings dissemination and study impact. Further, follow-up presentations of our findings are planned including a series of presentations in Alberta communities as well as at national and international venues, with the aim of broader impact. Additionally, we are aiming to publish findings in relevant academic journals and lay/regional publications. We have and likely will again present study findings and recommendations to the Alberta Alliance for Mental Illness and Mental Health (AIMIMH).

Beyond presentation and publication, the team is in the process of developing educational resources for professional, policy development and lay knowledge building and mobilization. As noted above, this includes the development of a toolkit for policy developers, practitioners and families guiding transition planning for the DDMI population in Alberta and beyond. We are further developing relevant clinical guidelines for practitioners based on study findings in which we intend to ultimately utilize a participatory action research approach to foster policy and practice development and application. This work reflects an attempt to obtain additional knowledge translation funding.

**ACKNOWLEDGEMENT**

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**PROJECT PARTNERS (TEAM MEMBERS)**
PUBLICATIONS AND PRESENTATIONS


ABOUT THE ALBERTA MENTAL HEALTH RESEARCH PARTNERSHIP PROGRAM
The Alberta Mental Health Research Partnership Program is comprised of a broad-based multisectoral group, representing service providers, academic researchers, policy-makers and consumer groups, working together to improve the coordination and implementation of practice-based mental health research in Alberta.

The mission of the Research Partnership Program is to improve mental health outcomes for Albertans along identified research priority themes, by generating evidence and expediting its transfer into 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 mental health research findings, and to better translate of these findings into practice improvements.
REFERENCES


