ASSERTIVE COMMUNITY TREATMENT—DUALLY DIAGNOSED: THE HYPHEN WAS THE EASY PART

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The efficacy of community-based Assertive Community Treatment (ACT), in supporting individuals with severe and persistent mental illnesses, has been well established in North America. Fidelity to established core principles of this modality of care has been demonstrated to optimize individual outcomes as measured objectively in a variety of life domains. Recent attempts have been made to extend ACT principles to groups of individuals with special needs, including the homeless, individuals with forensic histories, and individuals with developmental disabilities (DD). In response to two recent studies questioning the value to this approach of supporting individuals in the community with DD and mental health concerns, we conducted a naturalistic, retrospective chart review to demonstrate current characteristics of the population served by an ACT team mandated to provide care specifically to individuals with DD and mental health concerns. Reduced days of hospitalization, retrospectively measured pre and post engagement with the team clearly demonstrate value of this approach in supporting this group of individuals. Variations to fidelity principles deemed to optimize the fit between these principles and the unique needs of these individuals, their care providers, and families, are reviewed.
Keywords: intellectual disability, assertive community treatment (ACT), psychiatric disorder, schizophrenia, substance abuse, mood disorder

With the announcement in September 2004 by the Ontario Ministry of Community and Social Services, of a five year plan to close the three remaining institutions in Ontario, Canada in which individuals with intellectual disability and mental health concerns (ID-MHC) reside, the need for increased support options for these individuals, the majority with clinical diagnoses, has been amplified.[12] It is well documented that the majority of individuals remaining in institutions in Ontario have mental health concerns.[6] In addition, recent studies have demonstrated that a significant number of individuals with ID-MHC continue to reside in mental health facilities in Ontario.[8] The need to develop comprehensive support plans based on proactive needs assessments, combined with contingency funding for crises to support both these groups of individuals to optimize their quality of life during their transition to community settings, has been replicated in multiple studies.

A variety of community-based options for assisted treatment of individuals with serious and pervasive DSM-IV-TR[2] Axis I and Axis II diagnoses have been established.[3,14] The need for these options has been attested to by studies indicating that up to 40% of individuals with schizophrenia or bipolar disorders are at any time, not actively engaged in treatment, and that the 40% of individuals with these illnesses have a marked impairment of awareness or insight regarding various aspects of their illnesses.[1,5]

A recent meta-analysis of randomized trials of the impact of Assertive Community Treatment (ACT) compared to standard community care and case management, as well as traditional hospital-based rehabilitation, has confirmed the value of ACT principles in increasing client contact with support services, decreasing admissions to hospital, reducing time spent in hospital, improved accommodations, employment, and patient satisfaction.[9] Continued work is necessary to determine if ACT also offers true economic savings to mental health support systems.

Early studies of this model of care developed by Dr. Leonard Stein, Mary Ann Test and Arnold Marx in the early 1970's at Mendola State Hospital in Madison, Wisconsin, initially demonstrated the value of the ACT model.[18] Subsequent studies have, however, raised concerns that program drift may occur if the critical components of the service are not specifically operationally defined.[19] Program standards in Ontario regarding this treatment model have recently been revised, stressing the need to maintain fidelity to the core principles of ACT to optimize client outcomes.[17] The measurement of program fidelity was the impetus for the development of the Dartmouth ACT Fidelity Scale.[21] Modifications to this scale have suggested that chart review, team meeting

observations, home visits and semi-structured interviews with team leaders can be subjective methods of evaluating fidelity to the principles illustrated in Table 1.

Table 1. Core ACT Principles	
1.	Services are targeted to individuals with severe and persistent mental illness.
2.	Rather than brokering services, support and rehabilitation services are provided directly by the team.
3.	Team members share responsibility for the individuals served by the team.
4.	Small staff to consumer ratios is recommended.
5.	Treatment and services are to be comprehensive and flexible.
6.	Interventions are to be largely community-based.
7.	Services are not intended to be time-limited.
8.	Treatment and services are individualized.
9.	Services are available 24 hours per day.
10.	Assertiveness in engaging individuals and monitoring progress in their recovery is stressed.[17]

Recent studies have begun to address potential implications for offering ACT services to specific populations, including the homeless,[4] individuals with forensic histories,[13] and to a lesser extent, individuals with developmental disabilities.[9] Two recent British studies[10,11] failed to demonstrate significant differences in a variety of outcome measures comparing the provision of ACT support to individuals with mental health concerns and dual diagnosis to standard community treatment. These studies, however, were underpowered, acknowledged a potential lack of fidelity to ACT standards and the provision with ACT support, and stressed that existing standards of care in the United Kingdom for individuals with intellectual disabilities may in fact be more assertive in comparison to non-ACT modeled services in under-resourced areas in North America.

The purpose of the present report was to analyze the impact of a specialized ACT-DD (dual diagnosis) team on the quality of life of individuals with ID-MHC supported from 1998 to 2006. This chart review analyzed demographic data and core clinical outcome measures of importance to determine the impact of the team in supporting individuals in their community.

Method

The present study was a chart review of individuals served by the ACT-DD team conducted during the summers of 2004, 2005 and 2006. Demographic and clinical characteristics of individuals currently supported by the team were analyzed. In addition, the number of episodes of hospitalization, days of hospitalization, as well as days institutionalized pre- and post-engagement with the team, were retrospectively reviewed. At the onset it was formulated that treatment outcomes had benefitted from adaptations to some ACT principles made by the team, while otherwise attempting to adhere to core ACT principles. A total of forty-three charts were reviewed.

The ACT-DD team of the Brockville Mental Health Centre in Brockville, Ontario, Canada had its inception in 1998. Team members included a psychiatrist, nurses, social workers, a vocational specialist, a team leader, a family physician, and two behavioral technicians. The team was developed to fulfill the following mission statement:

To provide client-centered biopsychosocial interventions in supporting individuals with developmental disabilities and serious persistent mental illness through the provision of comprehensive community-based service. Goals of enhanced quality of life and the provision of dignity and community integration are pursued. During its evolution, the team, which now consists of a team leader, a part-time family physician, five RN's, community support workers, a vocational/leisure skills instructor, two social workers, two behavioral science technicians, and a consulting psychiatrist, have attempted to balance fidelity to core ACT principles with the recognition of the need for additional creativity and initiation to address needs specific to this group of individuals, or families and support circles. The team is supported by an Advisory Board with representation from Mental Health and Developmental Services, and services individuals located in a largely rural geographical area, spanning six townships with a combined population of 350,000 in Eastern

Ontario, Canada. The team daily faces the challenges of delivering services to individuals living in rural areas, often considerable distances from team offices.

Results

A total of 43 clients were reviewed with the following demographic characteristics:

GENDER:
Male - 31 (72%) • Female - 12 (28%)

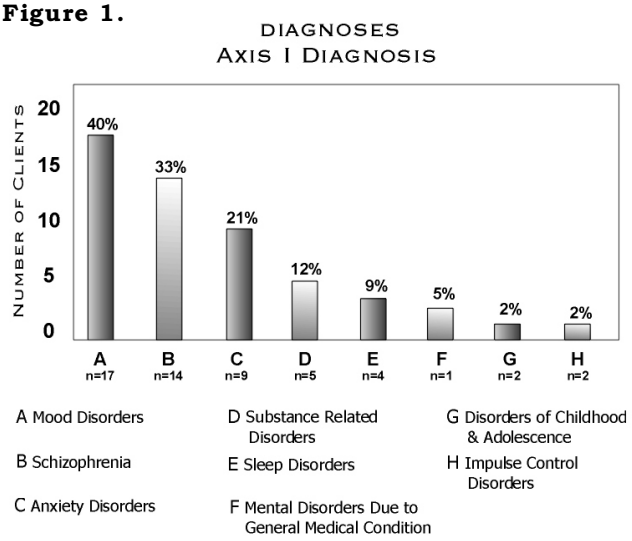
MARITAL STATUS:
Single - 39 (91%) • Married – 2 (5%)
Widowed – 1 (2%) • Divorced – 1 (2%)

AGE:
Mean – 43 years of age
Range – 17 to 66 years of age

SOURCE OF INCOME:
i. Ontario Disability, Support Pensions (ODSP)– 73%.
ii. A combination of ODSP and paid employment– 26%.
iii. Paid employment – 1%.

Axis I DSM-IV-TR[2] diagnosis of individuals served by the team are illustrated in Figure 1.

Figure 1.



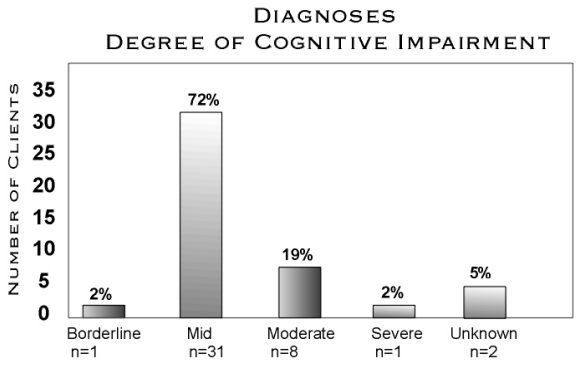
n>43 because of multiple conditions per person.

The team's experience has justified the modification of inclusion criteria to include individuals with challenging behaviors at intake, rather than established diagnoses of severe and persistent mental illness. Our experience, as supported by numerous studies in the literature,[15] is that the majority of individuals accepted over time clearly have Axis I DSM-IV-TR diagnoses. The absence of an Axis I diagnosis typically reflects the critically under-resourced subspecialty psychiatric care addressing the needs of mental health concerns of individuals with intellectual disability in the team's geographical catchment area, rather than the absence of a valid Axis I DSM-IV-TR diagnosis.

The addition of two behavioral science technicians to the team with expertise in developing operationalized definitions for potential signs and symptoms of hypothesized diagnoses, increasing the ability to perform functional behavioral analysis of challenging behavior and to develop behavioral and habilitative plans, including PRN protocols based on biopsychosocial principles, has contributed to positive treatment outcomes. These team members assist community-based support providers in implementing charting mechanisms, analyzing data over time, and assisting substitute decision makers in making informed decisions regarding treatment recommendations.[7]

Axis II diagnoses and the degrees of cognitive impairment in individuals supported by the team are illustrated below.

Figure 2.

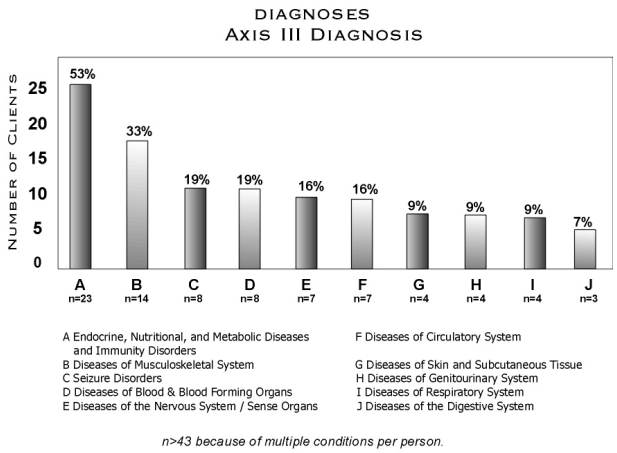


Of note, it is a fact that five individuals with autism spectrum disorders are supported by the team; this psychometric group of individuals, who are at risk of "falling between the cracks" if they are demonstrated psychometrically to have full scale I.Q.'s above 70, are supported by the team despite disqualification from community-based developmental services (unfortunately, psychometric results were unavailable).

A need for accessibility to a family physician familiar with the needs of individuals with dual diagnosis and expertise in mental health, as well

as skilled nurses with expertise in both physical and mental health nursing is attested to by the magnitude of Axis III diagnoses complicating the course of mental health concerns of individuals supported by the team. These are illustrated in Figure 3.

Figure 3.



n>43 because of multiple conditions per person.

The biopsychosocial approach offered by the team has proved most beneficial in meeting the complex needs of these individuals, often otherwise unable to access family physicians and often challenged to communicate their distress verbally.

The need for an interdisciplinary approach to care offered by the team is illustrated in Figures 4 and 5 demonstrating areas of support offered by the team.

Figure 4.

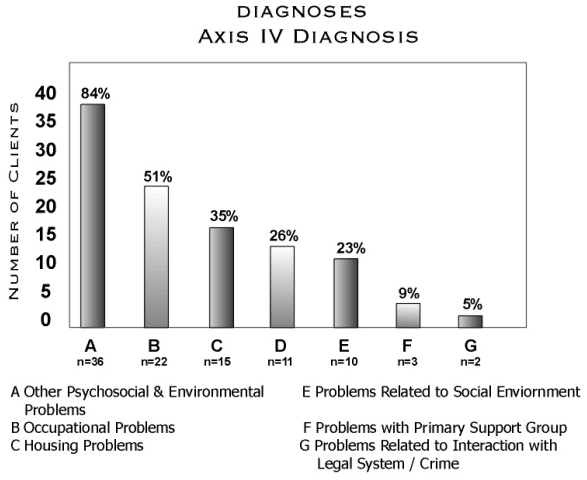
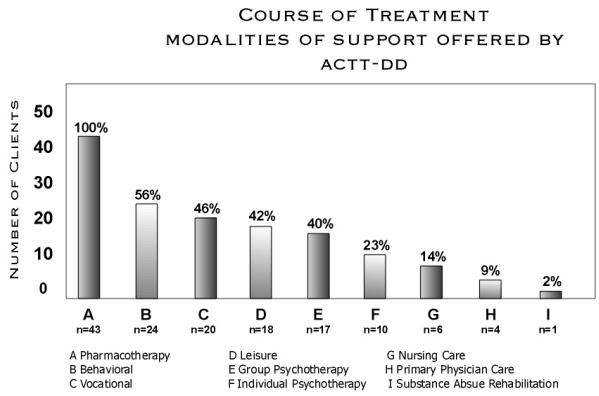


Figure 5.



n>43 because of multiple conditions per person.

The core team, however, continues to maintain, enhance and establish relationships with multiple community-based agencies. This is necessitated by the fact that developmental services and mental health services are funded by different government ministries in the team's jurisdictions; as is true in many areas in North America. Although contrary to core ACT principles, residential, systemic and individual advocacy needs of the team's cohort support this "lack of fidelity" to core principles.

In contrast, specific needs of the team's cohort, including a high instance of physical, emotional, financial, sexual abuse, and subsequent posttraumatic stress disorder, are well documented elsewhere,[16] and have been addressed by team social workers and other team members. These groups are being empowered to develop sub-specialty expertise in individual and group psychotherapy, therapeutic resources otherwise extremely difficult to locate.

The team's experience has interestingly demonstrated that few individuals supported by the team have, in fact, received genetic consultations to determine the etiology of their dual diagnosis and potentially associated physical and mental health phenotypes. Identified syndromes and diagnosed mental health concerns are listed below in Figure 6.

Fidelity to non time-limited treatment has been adhered to, to a large extent, allowing the development of trusting therapeutic alliances and the inclusion of proactive therapeutic principles in behavioral and crisis planning. Reasons for discontinuation of the team are illustrated in Figure 7, an indirect testament to client satisfaction with team support.

Figure 6.

Syndromes
Associated Psychiatric Diagnoses

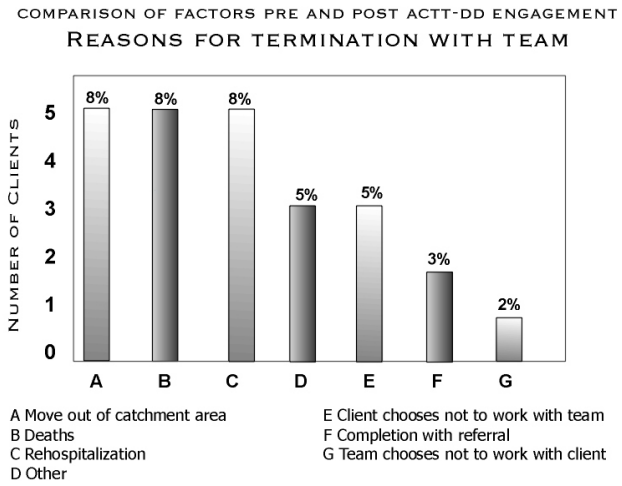
•Prader Willi Syndrome (n=1)
- ➢Impulse Control Disorder

•Fetal Alcohol Syndrome (n=2)
- ➢ADHD
- ➢Schizoaffective Disorder

•Fragile X Syndrome (n=1)
- ➢Major Depressive Disorder
- ➢Obsessive Compulsive Disorder

•Chromosome #9 Deletion (n=1)
- ➢Bipolar Affective Disorder
- ➢Impulse Control Disorder
- ➢Seizure Disorder

Figure 7.



A number of individuals referred to the team had experienced long periods of institutionalization in facilities for individuals with dual diagnosis, or had resided long-term at the psychiatric facility with which the team is affiliated. The degree to which engagement with the team has impacted on numbers of hospitalizations and days in hospital are illustrated in Figures 8 and 9.

In specifically analyzing the post-term engagement experience of a group of individuals who have had long-term stays of greater than one year in the facility (Figure 10), again the attainment of significantly improved community integration was achieved. It is important to recognize that the Brockville Psychiatric Hospital is a tertiary care psychiatric facility, which typically accepts admissions to a unit designed to address the needs of individuals with ID-MHC, through transfers from its admission unit or from psychiatric units located in general hospital settings throughout its geographical catchment area. The needs of individuals served by this facility are complex, resulting in persistent, greater than average durations of stay. This conclusion is supported by data regarding the number of admissions. Brockville Psychiatric Hospital accounted for the 54,019 days of hospitalization before ACT-DD team involvement with only 25 admissions, an average duration per admission of 2,160 days, or 5.9 years. After discharge, the number of days per admission was 57, or less than two months; a very impressive reduction, but still a significant length of stay compared to the other facilities (42 readmissions lasting 1,300 days, or 30 days per admission).

Figure 8.

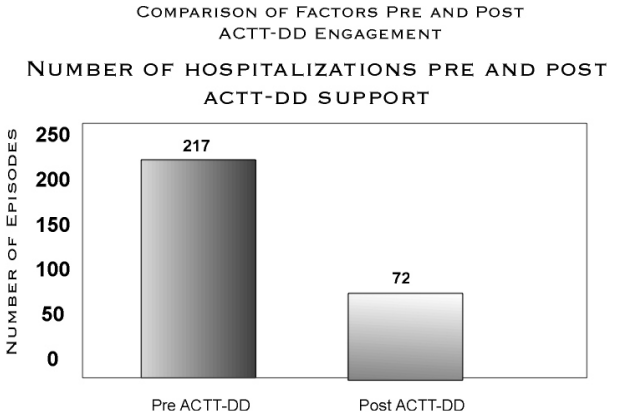


Figure 9.

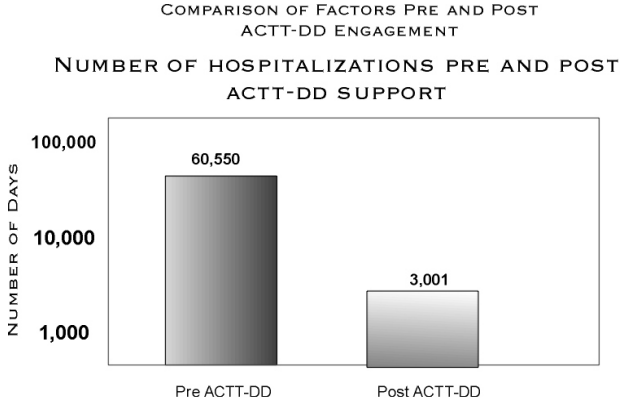
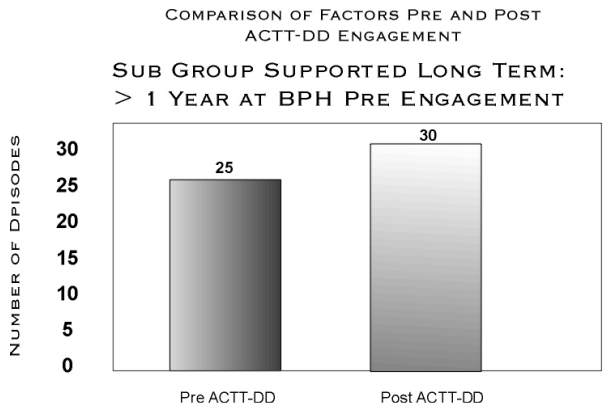
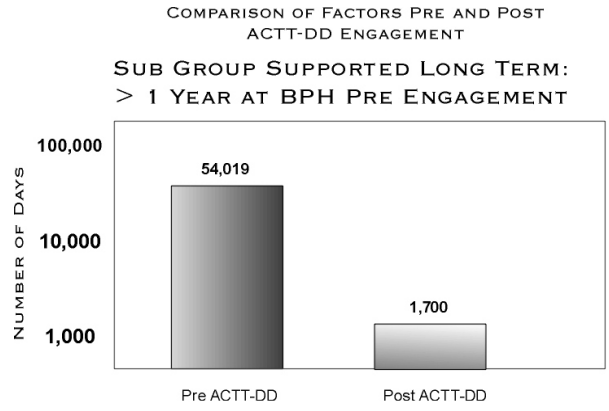


Figure 10.



The team believes that the noted increase in admissions (Figure 11) to an admission unit at the same facility reflects appropriate clarification of diagnosis and the natural history of these diagnoses, as opposed to a lack of comprehensive community-based support.

Figure 11.



Discussion

The experience of this team, although not measured specifically with a formal instrument of fidelity to ACT principles, supports the value of ACT support for individuals with ID-MHC. The well known biases inherent in completing a retrospective chart review are acknowledged. Despite this, the interdisciplinary, community and person-focused perspective of this concept and team are clearly documented. The significantly increased vulnerability of individuals with ID-MHC is again highlighted. The utilization of multiple modalities of support has had a dramatic impact on the number of admissions and durations of stay for the individuals reviewed.

The operational costs of an ACT team are high. However, although no formal cost analyses was completed, undeniable financial savings were realized over the time frame studied, due to savings related to reduced numbers of admissions to hospitals alone. The financial cost of improved quality of life for individuals supported by the team is immeasurable.

Walsh *et al.*[20] has reviewed the complexity of cost comparisons of support provided to individuals with intellectual disability in institutional versus community settings. They suggest that community settings are not inherently less expensive than are institutions, but also refute that centralization of services at institutions is more cost-effective. They realized that the more important questions are: "What does this person need? Where is the best place to provide for these needs, and at what cost?" (p. 117)

Variations to fidelity, which the team has found necessary, include:

1. Flexibility to admission criteria. This flexibility addresses misdiagnosis and the under-diagnosis of serious, persistent mental illness in individuals with ID-MHC.
2. The need to be flexible with respect to the maintenance of a "can-do-all approach" given the reality that developmental service and mental health service funding in the team's area of jurisdiction are provided by different government ministries.
3. The need to encourage sub-specialty areas of expertise amongst team members. In particular, fostering and cultivating expertise, through dedicating time for educational and program development and educational opportunities for behavioral specialists, skilled trauma psychotherapists, and skilled systemic advocates to address the unique needs of the population served by the team.
4. The need to educate hospital-based support teams regarding the needs of individuals with dual diagnosis and assisting in their support through extending the continuum of team support to individuals while hospitalized.
5. An awareness of the high incidence of abuse and post traumatic stress disorder in the team's cohort, and the need to develop specialized team facilitated resources to address these needs.

As the deinstitutionalization continues, the need for generic ACT teams is to be amplified. Their interest and expertise in supporting individuals with dual diagnosis will continue to increase. A client-centered, flexible, and innovative promotion of dignity and empowerment in community settings for individuals with serious and persistent mental illness is familiar to all ACT teams. Hopefully this commonality amongst all ACT teams will assist teams in accepting this challenge to extend their support modalities to individuals with dual diagnosis.

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