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Assertive Community Treatment Teams and Adults with Intellectual Disabilities

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Abstract

To determine the proportion of Ontario's assertive community treatment (ACT) teams' registered and wait-listed clients who have an intellectual disability, a brief survey was sent to managers or team leaders of all provincial teams. Of the 78 Ontario ACT teams, 85.9% participated. Overall, respondents estimated that 9.3% of their clientele have intellectual disabilities as did 10.8% of waiting list clients. Considerable unexplained variation in proportions was found when comparing teams and when data were aggregated by teams within provincial health planning authorities. Discussion of these results and recommendations for further study to determine the reasons for this variation are made.

Assertive community treatment (ACT) is internationally a well-established and effective model for providing intensive treatment and psychosocial rehabilitation services to people with severe and persistent mental illnesses (Allness & Knoedler, 1998). This type of treatment service usually involves an interdisciplinary team of professionals intensively serving a set number of voluntary clients with mental health (e.g., mental health assessment, psychotherapy, crisis supports, medication administration) and social rehabilitation supports (e.g., case management, social and life skills training, home and job finding efforts) in the clients' home environments. In Canada, the country of concern in this paper, various provinces (e.g., Newfoundland and Labrador, Quebec, Ontario, British Columbia) have implemented the specific ACT model version known as Programs of Assertive Community Treatment (PACT) originally developed in the U.S.A. in the 1970s (Stein & Test, 1980). The model has been shown to lead to significant reductions in psychiatric admissions and hospital stays and to improved housing stability, symptoms, and quality of life (Mueser, Bond, Drake, & Resnick, 1998). Through the frequent contact with team members, PACT clients are able to communicate their needs and have targeted supports more readily available and better coordinated than is commonly obtainable from other community-based mental health services.

Although assertive community treatment has been well studied in the general population in North America and parts of Europe, the Cochrane Review which examined ACT's effectiveness when used with persons with dual diagnosis compared to standard community treatment identified only two randomized controlled trials, both conducted in the U.K. (Balogh, Ouellette-Kuntz, Bourne, Lunsky, & Colanonio, 2009). People who have intellectual disabilities and serious

and persistent mental disorders represent one of the most challenging-to-serve populations and in Canada are often referred to as having a "dual diagnosis." Their cognitive and functional impairments are often compounded by stressors related to communication difficulties, socioeconomic disadvantages, inadequate housing and supervision supports, lack of access to case management and vocational services, and wide-spread discrimination.

Results from one U.K. study with 20 participants showed that there were no statistically significant differences between ACT outcomes and standard treatment outcomes in terms of quality of life, level of unmet needs, individual functioning, and carer burden (Martin et al., 2005), while a second study (with 30 participants) also found no difference on a similar range of outcome variables (Oliver et al., 2005). Oliver and colleagues (Oliver et al., 2005; Oliver, Piachaud, Done et al., 2002) noted a host of challenges regarding study ethics and randomization which likely impacted their study design and outcomes. Overall much more research was recommended to corroborate findings from the randomized controlled trials (Balogh et al., 2009).

In Canada, only one study has reported on an attempt to examine the effectiveness of an Ontario ACT team service designed especially for adults with a dual diagnosis (King et al., 2009). This study focused on profiling the team's client population, reporting service outcomes and recommending adaptations to the core ACT principles which were deemed by the authors as important (e.g., employing behaviour therapists, conducting significant in-reach to hospital, and enhanced advocacy efforts) when serving clients with dual diagnosis. The study cited a reduction in hospital admission to psychiatry units and decreased bed use when comparing clients' experiences pre-and post engagement with ACT services. However, significant methodological limitations (e.g., lack of reference to any statistical analysis, comparing outcomes over inconsistent time periods, lack of a control group for comparative purposes) hamper the ability to draw definitive conclusions about the effectiveness of such a team. While significant gaps exist in the professional literature about the efficacy of ACT services for adults with dual diagnosis, we do know anecdotally that many individuals with intellectual disabilities benefit from such services and many more are likely to need such intensive services.

While Health Canada (1988) suggested that at least 0.8% of the Canadian general population has an intellectual disability, studies have shown that people with intellectual disabilities experience mental disorders at about double the rate of other citizens (i.e., 38–39%) (Ouellette-Kuntz & Bielska, 2009; Yu & Atkinson, 1993). Research from Ontario reported that people with dual diagnosis accounted for 2.5% of inpatient admissions to a general hospital psychiatric unit over a 4-year period (Burge et al., 2002) and 18% of all inpatients at the nine regional provincial psychiatric hospitals (Lunsky et al., 2006). No information has been reported to date concerning the proportion of the province's 78 ACT team clients who have a dual diagnosis. Recognizing this dearth of information about dual diagnosis and ACT teams generally and in Canada specifically a preliminary survey was launched in Ontario to uncover data which could be used to inform subsequent research efforts.

Methodology

Survey Administration

A brief questionnaire was devised with input from the Technical Advisory Panel for Ontario's ACT teams (TAP). The TAP is an Ontario committee composed of agency administrators along with government representatives from the Ministry of Health and Long-Term Care and others to offer advice concerning research and practice effecting ACT teams and clients in Ontario. Following the reception of study approval by the TAP and ethical approval by the Faculty of Health Sciences' Research Ethics Board of Queen's University, the survey was sent by the Chair of the TAP, in late-June 2009, to Ontario's 78 ACT team leaders or managers for self-administration and direct return to the author. Several reminders were sent in advance of the survey collection end date. Completed surveys were received over a seven-week period from June 29 to August 17, 2009.This study was completed without dedicated funding.

Research Instrument

This English-language survey had introductory instructions which included quoted American Psychiatric Association (2000) criteria for the diagnosis of Mental Retardation (Note 1), a listing of inclusionary diagnoses (i.e., Mental Retardation, Autistic Disorder), an exclusionary diagnosis (e.g., Asperger's Disorder), six questions about client numbers and training needs; and required about 10 minutes to complete. This brief communication focuses on the responses to the four questions concerning active client loads, wait lists and estimated numbers for each concerning clients with dual diagnosis (for the full report see Burge, 2009). It was considered important to use the actual DSM-IV terminology in the survey as the commonly used, often considered less derogatory, alternative terms of "developmental disability" and "intellectual disability" have confusing meaning to some people and do not always connote the presence of a significant cognitive disability.

Analysis of Data

The TAP requested that data for teams be aggregated by the level of local health planning authorities (i.e., Local Health Integration Networks (LHINs)) (Ontario Ministry of Health and Long-Term Care, 2010). Descriptive analyses (e.g., frequency distributions, percentages etc.) were computed.

Results

Of 78 existing Ontario ACT teams, 67 participated, making the participation rate 85.9%. Seven of the 13 LHINs had participation of 100% of area teams. The participating teams ranged widely in the number of clients served—from 25-135, with an average of 67 clients per team.

Clientele

Overall, 4429 clients were served and 414 or 9.3% of these were estimated to have a dual diagnosis. The participating teams ranged widely in the number of clients served who were estimated to have a dual diagnosis—from 0-38 (*M*=6). When the one team which serves only individuals with dual diagnosis (sponsored by a Champlain LHIN hospital) was excluded the range was 0-30 (*M*=5.7). Table 1 lists the aggregated ranges.

Table 1. Ranges of clients with a dual diagnosis served by teams (N=67)

Number of clients served estimated to have a dual diagnosis	*Teams # (%)*
<3 clients	23 (34.3%)
4–5 clients	21 (31.3%)
>6 clients	23 (34.3%)
Total	67

The number of teams serving clients with a dual diagnosis across three client number ranges is given in Table 1. Four of the 23 teams included in the category of serving fewer than 3 clients with a dual diagnosis, actually served a combined total of 272 clients, and had no clients estimated to have a dual diagnosis. Five of 23 teams included in the category of serving more than 6 clients with a dual diagnosis actually served more than 15 such clients each.

The proportion of clients with a dual diagnosis who were served, ranged widely, from 0 to100%. When the specialty "dual diagnosis" ACT team was excluded, the highest proportion who were served was 33%. In any given LHIN, the highest and lowest proportions of clients served by all teams were 19% in the South East LHIN and 5.2% in the Central East LHIN, respectively. Table 2 summarizes, by LHIN area, the final number and percentage of participating teams, the total number of clients served, and the number and proportion of team clients with a dual diagnosis.

"Figure 1 depicts the proportion of clients estimated to meet criteria for a dual diagnosis by LHIN area.

Waiting List Clients

Of the 67 teams only 42 (62.6%) indicated that they had any potential clients formally approved and on a waiting list for services. For these 42 teams, the total number of waiting cli-

Table 2. Proportion of clients with a dual diagnosis by LHIN (N=4429)

LHIN region number	*LHIN name*	*# of teams in region*	*# of teams participating in survey (%)*	*# of clients served by participating teams*	*# of clients with a dual diagnosis*	*Proportion of clients with a dual diagnosis*
1 & 2	Erie St. Clair & South West	14	12 (85.7)	897	49	5.5%
3	Waterloo Wellington	3	3 (100)	161	9	5.6%
4	Hamilton Niagara Haldimand Brant	6	5 (83.3)	363	33	9.1%
5	Central West	4	4 (100)	205	15	7.3%
6	Mississauga Halton	3	2 (66.7)	170	17	10.0%
7	Toronto Central	6	3 (50.0)	240	24	10.0%
8	Central	8	7 (87.5)	418	24	5.7%
9	Central East	6	6 (100)	328	17	5.2%
10	South East	5	5 (100)	400	76	19.0%
11	Champlain	10	10 (100)	679	97	14.3%
12	North Simcoe Muskoka	3	3 (100)	169	20	11.8%
13	North East	7	4 (57.1)	231	23	10.0%
14	North West	3	3 (100)	168	10	6.0%
	Sample Total	78	67 (85.9)	4429	414	9.3%

Note: Teams were placed in the LHIN corresponding to the catchment area where their sponsoring agency was located. Approximately 7 teams have catchment areas outside of, or partially outside of, the LHIN of this sponsor. Since the LHIN named Erie St. Clair has only 1 ACT team operated by a local sponsoring agency, it was combined with the adjoining LHIN, South West, to ensure team specific results could not be identified.

ents ranged from 1-70. A total of 26 (61.9%) of teams with a waiting list had fewer than 5 waiting list clients each. In total, 387 waiting list clients were identified for the province's teams. A total of 38 of these waiting list clients were estimated to have a dual diagnosis. Since two respondents were unable to estimate whether any waiting list clients had a dual diagnosis, their teams' data were excluded from the calculation of the proportion of waiting list clients with a dual diagnosis, which was 10.8%. For the other 25 teams, in several instances respondents reported that waiting lists were not kept.

Discussion

The study's key finding is that though people with intellectual disability make up a small proportion of the Ontario general population, they account for a sizable proportion of those served by ACT teams. While people with intellectual disabilities live across all communities in Ontario, surprisingly, teams within LHINs varied markedly regarding the proportion of clients they serve who have a dual diagnosis. Though the Ontario government has clearly stated in its 1999 implementation plan for mental health reform policy that adults with dual diagnosis are a first priority population and eligible for ACT team services (Ontario Ministry of Health and Long-Term Care, 1999), the reasons for this sizable variation remain unknown. The proportion of served clients estimated to have a dual diagnosis coupled with our findings regarding waiting lists suggests that it is very likely that Ontario ACT teams will contin-

ue to serve a similar proportion of clients with a dual diagnosis for the foreseeable future.

There may be a host of regional and local differences in the populations, service mix factors, and historical influences impacting rates of clients with a dual diagnosis, such as the locations of former residential institutions for people with intellectual disabilities and the regions where such individuals were repatriated to in recent years. As well, though inpatients at long-stay psychiatric hospitals are intended to be discharged to their former communities, given that adults with dual diagnosis tend to have longer lengths of stay (Lunsky et al., 2006; Saeed, Ouellette-Kuntz, Stuart, & Burge, 2003), it is possible that they have more frequently remained in communities where the hospitals are located. Though Ontario has a few specialty dual diagnosis consultation outreach teams, their catchment areas (e.g., Toronto Central LHIN, South East LHIN, Chaplain LHIN) do not appear to associate with lower rates of clients estimated to have dual diagnosis on the respective LHIN ACT teams.

Given that several teams reported caseloads with no or very few clients with dual diagnosis, obvious questions emerge. Are substantial numbers of people with a dual diagnosis in those catchment areas experiencing significant unmet needs for ACT with resultant personally detrimental effects as well as costly and unnecessary service system impacts? Are other services or service models (e.g., Developmental Services Workers, Adult Protective Service Workers, Intensive Case Management Teams) in those areas adequately providing for the needs for intensive and assertive mental health supports?

Study Limitations

Results from three LHINs, with less than a 70% team participation rate, may not be reflective of their total LHIN teams' experiences. The survey relied on the estimates provided by man-

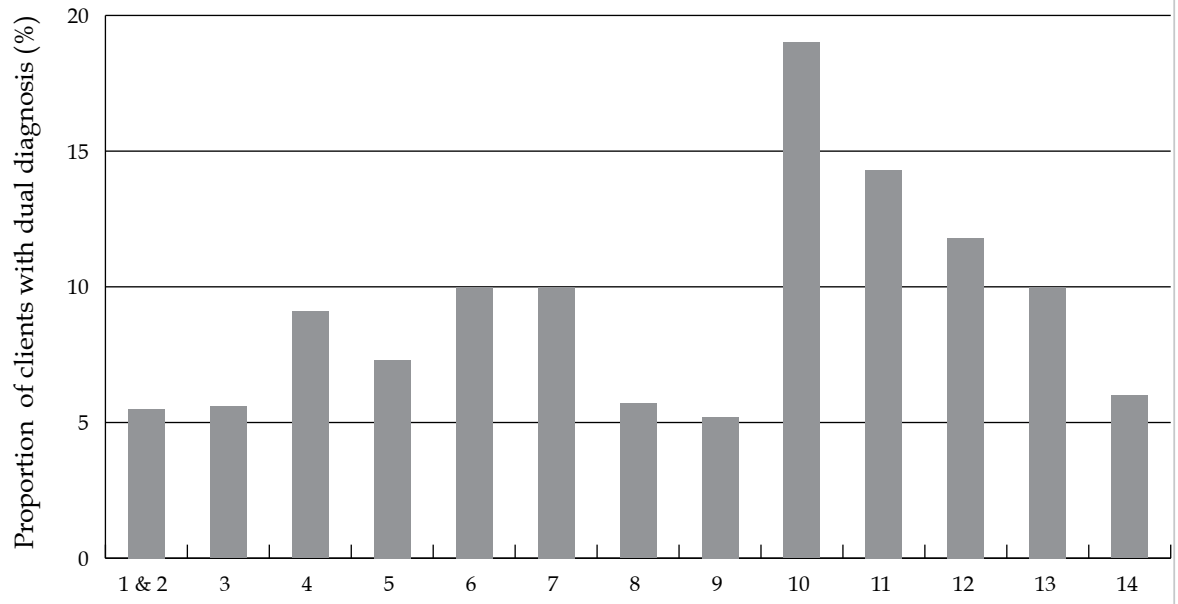

Figure 1. Proportion of ACT team clients estimated to have a dual diagnosis by LIHN (N=4429)

Note: Teams were placed in the LHIN corresponding to the catchment area where their sponsoring agency was located. Approximately 7 teams have catchment areas outside of or partially outside of the LHIN of this sponsor. Since the LHIN named Erie St. Clair has only 1 ACT team operated by a local sponsoring agency, it was combined with the adjoining LHIN, South West, to ensure team-specific results could not be identified. Legend: 1 & 2=Erie St. Clair & South West, 3=Waterloo Wellington, 4=Hamilton Niagara Haldimand Brant, 5=Central West, 6=Mississauga Halton, 7=Toronto Central, 8=Central, 9=Central East, 10=South East, 11=Champlain, 12=North Simcoe Muskoka, 13=North East, 14=North West. The only specialty dual diagnosis ACT team is counted in the Champlain LHIN.

agers or team leaders and did not employ independent clinical assessments or file reviews to determine which clients did and did not meet criteria for a dual diagnosis. It is possible that some respondents over or under-estimated the number of clients with a dual diagnosis served by their team. However, there is no reason to suspect that any inaccuracies would be evident across multiple teams in certain LHIN areas versus others and explain a 14% difference between the LHINs. Information on waiting lists was impacted by a number of factors (e.g., whether teams kept such lists) and related data were therefore only examined grossly and not by LHIN. Notwithstanding these potential limitations, we are confident that the findings presented here are a reasonable reflection of the province-wide experience of ACT teams.

Further Research

Further research should attempt to answer the following key question: Why is there considerable variability among teams regarding the proportion of clients with dual diagnosis served? Research is needed to identify the contributing factors (e.g., service system gaps or abundance of resources, client profiles, and discrimination by either referees and or ACT team clinicians). Furthermore, there is a pressing need to adequately evaluate the one Ontario ACT team designated to serve only clients with an intellectual disability in order to clarify if there are any specific client outcome benefits arising from such dedicated teams versus client outcomes for those with intellectual disabilities services by other ACT teams. In the regions of Ontario where few ACT clients are served it would be helpful to know if other service models are effectively treating and supporting those with a dual diagnosis.

Conclusion

Thousands of Ontario's adults with a dual diagnosis, currently living in psychiatric hospitals or in the community, are likely in need of access to intensive community-based services such as those provided by ACT teams. In some regions of the province very few of these adults are receiving this key service component meant to be available in every community and equitably to citizens who meet eligibility criteria.

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Note: Though use of the term Mental Retardation is offensive to many people it remains official terminology (i.e., DSM-IV) used in the mental health sector when referring to formal diagnoses and therefore was essential to include in the study.

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