

Survey on Substance Misuse and Persons with Intellectual Disability in Southeastern Ontario

Views on Services

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Study Report

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Introduction

This report presents information gathered in the Survey on Substance Misuse and Persons with Intellectual Disability during January to May 2012. In particular, the survey was concerned with the experiences and views of clinicians and staff members working in Southeastern Ontario working with clients with intellectual disabilities, dual diagnosis or substance misuse issues. A person may be described as having a 'dual diagnosis' when he or she has two or more diagnosed mental disorders with at least one of these disorders being either Mental Retardation¹ or Autistic Disorder as per the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (American Psychiatric Association, 2000).

The Survey's aims were to gauge the views from managers and staff members of mental health and social services agencies and hospitals in Southeastern Ontario concerning:

- a) the estimated size of the substance misuse problem amongst adult clients with an intellectual disability they serve
- b) the satisfaction with existing clinical treatment services that may exist for substance misuse problems with adults with an intellectual disability in the region
- c) the relative need for and nature of services that may be developed to address this clinical issue

Why this Survey?

The issue of substance misuse among persons with intellectual disability has been a common one concerning mental health and addictions clinicians and developmental services staff. Clinicians and staff members, known to the authors, from time to time anecdotally reported on professional difficulties experienced when attempting to treat, find appropriate treatment or support clients with intellectual disabilities and substance misuse problems.

Knowledge of the mental health service treatment needs of segments of the population is valuable information for service planning. To date, there has been no regional research to indicate the use of substance misuse services by people with intellectual disabilities or to examine views of clinicians and other staff about the adequacy of related services in Southeastern Ontario.

In fall 2011 a small committee of clinicians and managers were invited by a Coordinator of the Eastern Region Community Network of Specialized Care (CNCS) to a meeting concerning substance misuse services and training. The group was interested in ensuring that adequate treatment services exist in the Southeast region and met to discuss views on service level

¹ Though use of this term is offensive to many people it remains official terminology often used in the mental health sector when referring to diagnoses and therefore was essential to include in the study. This report frequently replaces Mental Retardation and Autistic Disorder with 'intellectual disability'.

adequacy and possible future training possibilities to be coordinated for area staff at no cost or nominal cost. The planning group decided to support the administration of a brief and simple survey to obtain information from area staff and managers about the population of interest and the relative need for substance misuse services for this group. Therefore, this survey was initiated through discussions between the original seven members (see Appendix B) of an ad-hoc Committee on Dual Diagnosis Substance Misuse for Southeastern Ontario to begin to fill the significant information gaps noted above and to create supportable recommendations to further advances in service, training, and education.

Rates of Intellectual Disability, Dual Diagnosis, and Substance Misuse Among Ontarians and Canadians

The percentage of the Ontario population who has an intellectual disability has been estimated variously between approximately 1-2%. Few sources of information are available regarding the rates of dual diagnosis among Ontarians. In Canada, government health ministries, both provincial (i.e., Ontario) and federal, do not gather and make available such information. A number of research reports and journal articles have reported on dual diagnosis rates amongst certain subsections of the Ontarian population. It has been estimated that about 39% of those with an intellectual disability in Ontario likely have another mental disorder: dual diagnosis (Yu & Atkinson, 1993). An administrative prevalence study conducted in Southeastern Ontario arrived at an estimate of 38% of those with an intellectual disability also having a psychiatric or behavioural concern listed (Ouellette-Kuntz & Bielska, 2009).

Amongst the general Canadian population, the rate of substance misuse has been recently measured via the Canadian Alcohol and Drug Use Monitoring Survey (CADUMS - 2009) prevalence data for various substances including alcohol varied. The survey is completed approximately every five years and records national and provincial estimates of alcohol and illicit drug use by age and region among Canadians aged 15 years and older.

In all recorded categories of substances, the youth surveyed consistently accounted for significantly higher levels of use and misuse. Alcohol is by far the substance of choice, recreationally and in terms of misuse. A total of 76.5% of Canadians reported drinking alcohol. Those identified with heavy frequent drinking patterns among youth (i.e., age 15 to 24) accounted for 11.7% which was three times higher than the rate for adults 25 years and older at 3.9%. A further 3.7% identified heavy but infrequent use (i.e., binge drinking), however, the vast majority reported drinking alcohol and experiencing no consequences of misuse.

Cannabis use among Canadian youth was also significantly higher than adults (approximately 3 ½ times higher). Fully one quarter of respondents indicated that they had used a psychoactive pharmaceutical drug (e.g., opioid pain relievers, stimulants, tranquillizers and sedatives) in the past-year, and again adults accounted for a much smaller percentage of misuse (i.e., 2.3% used such a drug to get high versus 9.5% for youth). Of the three categories of pharmaceuticals,

opioid pain relievers were used most commonly. The prevalence of abuse was roughly six times higher among youth, 15 to 24 years of age.

Some studies on rates of substance misuse among persons with intellectual disabilities have been reported in the professional literature in recent years. A 2006 American study which reviewed this research identified a number of major methodological shortcomings in prior literature and very limited numbers of studies overall. The author concluded in summary that , “Overall, findings from these studies suggest that adults with MR use alcohol and other drugs at somewhat lower rates than nondisabled adults” (McGillicuddy, 2006, p. 44). No comprehensive review of related research will be included here. While some other studies have been published since 2006 none have focussed on Southeastern Ontario.

Summary

Considerable gaps exist in our knowledge of rates of citizens who have an intellectual disability and substance use and misuse problems and especially whether existing services are adequate to address the needs of such clients. We have currently no reliable province-wide data on this sub-population.

Research Methodology

This simple research methodology using a cross-sectional design is presented through a reporting of the study sampling, procedures, analysis plan, and ethical considerations.

Sampling

The sampling plan was to invite participation of all managers or team leaders for Southeastern Ontario's developmental services and mental health treatment and addictions services providers. According to the Ontario Ministry of Community and Social Services there were a total of 36 agencies and hospitals receiving developmental services program funding in fall 2011 when the study was being conceived. One of these funding recipients was a small rural acute care hospital, which was later excluded from our survey list. A total of 6 other social service or mental health agencies and hospitals, funded by the Ontario Ministry of Health and Long-Term Care either directly or via the Local Health Integration Network, were added to the sample to target the inclusion of information from and views of mental health and addiction treatment providers throughout the region. In total, 41 agencies and hospitals were invited to participate.

Survey Instrument

The brief survey (Appendix A) was comprised of a preamble which outlined the definition of intellectual disability inclusion and exclusion criteria and substance misuse. A brief quotation from the DSM regarding these criteria for Mental Retardation was included. The survey form was comprised of 12 brief questions. The questions covered three main areas as per the study purpose:

1. the estimated size of the substance misuse problem amongst adult clients with intellectual disability served by respondents' programs
2. the degree of satisfaction with existing clinical treatment services for substance misuse problems of adults with intellectual disability in the region
3. the relative need for and nature of services that may be developed to address this clinical problem

Use of Terminology

Citizens who receive services funded by the province for people with intellectual disabilities generally abhor being referred to by the DSM official diagnosis label 'Mental Retardation'. For this reason, the reader will find that it is only used in this study report when it refers to the DSM label. It was considered important to use the actual DSM terminology on the definitions portion of the survey form as the commonly used, often considered less derogatory, alternatives of 'developmental disability' and 'intellectual disability' have confusing meaning to some people and do not always connote the presence of a significant cognitive disability. In previous studies, confusion about such terminology among respondents has resulted in less accurate or less useful data being collected. Internationally, there is a trend toward use of the label

'intellectual disability', when a label is necessary to use, in academic and mental health circles instead of 'mental retardation' or 'developmental disability'².

Procedures

Planning Phase

A brief planning phase preceded the gathering and analysis of data. During this phase a brief review of the international professional literature on dual diagnosis and substance misuse occurred. The six members of an ad-hoc Committee on Dual Diagnosis Substance Misuse for Southeastern Ontario met to contribute to the planning for this survey and a related training activity. Ethical approval for the study was sought separately and granted by the Faculty of Health Sciences Research Ethics Board of Queen's University, Providence Care Mental Health Services and Quinte Healthcare Corporation. No funding was sought or received for this research. The involvement of two Occupational Therapy (OT) students enrolled at Queen's University and on a placement supervised by one of the Committee members was planned.

Data Collection Phase

Standard survey methods were adopted which included the self-administration of an easy to complete brief survey. An introductory letter and information about the study was mailed electronically to executive directors of the 46 developmental services agencies and mental health and addictions treatment services or hospitals in the catchment area of Southeastern Ontario in December, 2011. In January 2012 the introductory letter describing the survey purpose and background information along with the survey was sent to the recipients noted above.

A reminder email was sent to directors on January 23, 2012 and a second reminder was sent a few weeks later. A few potential respondents were also contacted by the two Occupational Therapy students under supervision and another assistant and reminders were given. In approximately four instances the students assisted respondents in survey completion by telephone. Most surveys were received by mid-March, 2012 though three respondents submitted surveys in early May and these were included.

Analysis of Data

All statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS) software. Given the nature of the survey, only descriptive statistics were computed. Descriptive analyses (e.g., frequency distributions, percentages etc.) were performed for each of the study variables related to the previously stated study questions. Programs were grouped by sector (i.e., developmental services or mental health and addictions) and later by county.

² The Ontario government's administrative term remains 'developmental disability' and is defined using equivalent criteria to the DSM's label 'Mental Retardation'. See Brown & Percy (2007) for a detailed discussion of related terminology.

Ethical Considerations

All procedures were reviewed and approved by the Research Ethics Board of the Faculty of Health Science of Queen's University and Providence Care Mental Health Services in late 2011 and in early 2012 by Quinte Healthcare Corp. Anonymity of any service recipients was ensured as only respondents estimates (i.e., of numbers of clientele) or views about service adequacy etc. were requested. No respondents' clients' names or details were ever shared. As well, a commitment was made by the researchers to ensure agency program or full agency and data could not be readily attributable. In general, we report on aggregated data with the smallest unit being that of a county which had multiple respondents.

Findings

Participating Agencies / Hospitals

Of the 41 agencies and hospitals invited to participate, 25 completed a survey for a participation rate of 60.9%. Non-participating agencies and hospitals were spread from across all 6 counties. Three large agencies or hospitals responded with multiple survey responses each with data concerning one program from among the various separate programs they offer. These three agencies / hospitals submitted a total of 14 surveys. In all, 36 completed surveys were received from the 25 participating agencies and hospitals.

Of the 36 programs with completed surveys, 30 programs were delivered to adult residents in one of the 6 counties of the Southeast Region while 6 programs served clients from across 2 - 6 county areas in the Southeast. Below, Table 1 identifies the number of the 36 respondent programs operating in each of the 6 counties of the region.

Table 1

Participating Programs Operating in the Southeast

Region by County

County	Total # of programs offered
Hastings	11
Prince Edward	5
Lennox & Addington	8
Frontenac	15
Leeds & Grenville	9
Lanark	5
Total	53

Note: Six of the 36 programs had catchment areas that spanned 2 – 6 counties.

Clients Reported On

Data collected from respondents indicated that their agencies / hospitals included programs served a wide range of total current clients. One served as few as 17 clients while another served as many as 1366. The total number of clientele served by the combined 36 programs was 4627. The number of clients they served who had a diagnosis of intellectual disability or were

suspected of qualifying for one was estimated by respondents to be 1328 (28.7%). Of the 4627 total clients served about 106 (2.3%) had an intellectual disability *and* also had a substance misuse issue in the past 6 months. Table 2 summarizes this data.

Table 2

Clients Reported On

Total # of clients	Total # (%) of clients estimated to have ID	# (%) estimated to have ID and a substance misuse
4627	1328 (28.7)	106 (2.3)

Viewed separately, of the 1328 clients who had an intellectual disability, the percentage estimated to have had a substance misuse issue in the past 6 months was estimated to be 8%.

Direct and Appropriate Treatment

Of the 35 respondents to the question regarding whether their agency / hospital provides direct treatment services to adults with intellectual disability, 25 (71.5%) reported they did not and 7 (20.0%) answered affirmatively while 3 (8.6%) responded that it was not applicable to them.

Appropriate treatment services (e.g., 12 Step programs (NA, AA), addictions counseling) for respondents' clients with intellectual disability and substance misuse problems were noted to exist by 16 (47.1%) respondents while 11 (32.3%) said they were lacking. Seven respondents (20.6%) responded that this question was 'not applicable' and in every case this response related to their lack of recent experience with any clients with intellectual disability and substance misuse problems.

Accessing Treatment Services Elsewhere

When asked whether they had been successful in accessing these services elsewhere for their clientele with intellectual disability, 12 (34.3%) respondents noted that they had not been successful, and 12 (34.3%) had been successful in accessing services. One respondent indicated that there had been success in one portion of their catchment area but not in another more rural area. Ten respondents indicated that this question was not applicable and in some cases this response appeared to relate to a lack of clients with intellectual disability and substance misuse issues in the past six months while other respondents agencies providing the services so had not sought out such services elsewhere.

Challenges or Obstacles

Respondents were asked via an open-ended question; whether or not their program provides addictions treatment services for adults with intellectual disabilities, what challenges or obstacles had the program staff experienced in providing or accessing elsewhere these services? Responses were examined and assigned to key theme categories.

Table 2 Challenges and Obstacles in Provision of or Access to Treatment Services

<i>Theme</i>	<i>Respondent Comment / Example</i>
Lack or Insufficient Knowledge of ID	-Staff members' lack of knowledge of substance misuse problems and we may miss identifying clients in need
Limited Resources	-Lack of availability of treatment programs generally or specialized resources (i.e., DD) specifically -Lack of training, appointments, assessment tools, limited resources (e.g., residential treatment). -Finding staff that are competent in dealing with developmental disability -The support person or parent not follow through with intake or treatment process -People with ID don't readily fit "into" existing programs for substance misuse -The tailoring of programs to meet the needs of clients with developmental disability; client having to "fit in" with services/programs that presently exist -Resources are stretched for all and our clients require a huge investment of time in order to succeed -Restrictive definitions of clients supported by particular agencies result in our agency holding onto clients normally referred. -Housing jeopardized, lack of housing, no in-treatment programs for this group.
Limited Training	-Finding appropriate and valuable training opportunities for staff regarding how to most effectively work with tri-diagnosis. -Whether counsellors at our local addictions centre would have the expertise to assist someone with a developmental disability experiencing an addiction problem. -Our deficit in DD is mirrored by deficit in other agencies with substance abuse counseling.
Lack of Experience / Comfort in Working with Persons with ID	-Group leaders, mentors or other group members are not familiar or comfortable with people with developmental disabilities
Perceived Limitations of Persons with ID	-Individuals have little or no insight needed in order to benefit -Deciding to not attend such recommended treatments -Courses are offered in evenings which is not convenient for most persons with ID -We run many groups and it is difficult for clients with DD and substance issues to a) comprehend information in group settings b) social skills difficulties -Past clients' ASD stresses providers as can be perseverative; clients poor time management skills lead to exclusion from services

Factors Promoting Success

Respondents were asked; whether or not their program provides addictions treatment services for this group, what challenges or obstacles has the program staff experienced in providing or accessing elsewhere these services? Table 3 summarizes question responses on this item.

Table 3 Factors Promoting Success

<i>Theme</i>	<i>Respondent Comment / Example</i>
Cross-Sectoral Partnerships	<ul style="list-style-type: none"> -Our strong relationship with / between developmental services agencies and addictions agencies -Having agencies that are committed to this population with a willingness to partner with other community agencies to provide a unified treatment plan and follow-up support.
Training	<ul style="list-style-type: none"> -Therapists familiarity with various disabilities, ability to present information based on individual learning styles and understanding level -Trained staff in substance misuse would provide some success as well as trained professionals that work with people that have DD - A course or teacher that really understands our clients and presents a program geared to the client's mental level.
Housing	<ul style="list-style-type: none"> -Appropriate housing, specialized training in substance use & developmental disabilities
Supports during Treatment	<ul style="list-style-type: none"> -Slow and steady, consistency/flexibility with worker and taking time to build rapport with client. Working hard to overcome issues of comprehension of concepts re addictions recovery: maintaining consistency with appointments and follow through. -Design of treatment needs to be inclusive and allow for trained support staff/volunteer -Ability to provide 1:1 staff support and transportation -increased supervision to ensure they attend as scheduled and programs geared to their functioning level would help ensure increased success
Enhanced and Accessible Treatment	<ul style="list-style-type: none"> -Being able to take someone for treatment who is agreeable at that exact time rather than having to wait for assessments or appointments

New Treatment Services

Respondents were asked whether any new substance misuse treatment services created for persons with intellectual disability to access, should be specialized (i.e., only for persons with intellectual disability) or wholly integrated into existing services / programs. Of the 35

respondents to this question, 23 (65.7%) reported they should be wholly integrated- 2 of these respondents added the proviso that the staff need to be well trained for this population. Nine (25.7%) viewed specialized intellectual disability services as being best and 3 (8.6%) responded that it was not applicable to them.

Discussion

The Survey on Substance Misuse and Persons with Intellectual Disability in Southeastern Ontario appears to be the first and only examination, of which the authors are aware, of its kind in Southeastern Ontario and has potential implications for future service delivery. Importantly it established an estimated rate of substance misuse (8%) amongst a sizable portion of the social services and clinical services clients in the region.

Taken together, respondents have identified a range of key factors which promote successful treatment and supports for those with intellectual disabilities and substance misuse. Some of these are factors that we note have been consistently and previously identified in numerous venues (e.g., focus groups, workshops, online presentations) as important to promoting successful work generally with persons with intellectual disabilities across developmental and mental health and addictions sectors. Therefore it is not surprising to hear that they are also endorsed as beneficial when focusing on persons with intellectual disabilities and substance misuse issues. Nevertheless, many respondents to our survey reported on considerable lack of available and appropriately geared treatment services for their clientele in the region. It is unclear whether some respondents were simply not aware of available services or how some of the existing services may be able to adequately address the needs of a portion of this population. For those service providers of substance misuse treatments it may be useful that they seek renewed opportunities for informing the community members and their cross-sectoral colleagues of their services' existence and inclusion criteria.

If indeed, as it appears, services are lacking in significant portions of the region or for subgroupings of those with intellectual disabilities it will be important for government regulators from both ministries along with program planners, administrators and clinicians to engage in eliminating such serious programmatic gaps. As well, considerable support was found here for cross-sectoral training to ensure available or newly developed services adequately meet the service needs of those with intellectual disability.

Study Limitations

The study findings may have been impacted by a few limitations. First, while the participation rate of agencies / hospitals teams was relatively high several large agencies or hospitals had representation by only certain programs though participation of many more programs would have been deemed as optimal and beneficial to the authors. Therefore, it is possible that responses do not adequately reflect views of service providers in some county areas.

Also, the survey results relied on the estimates provided by staff and did not employ independent clinical assessments or file reviews to determine which clients did and did not meet criteria for an intellectual disability or substance misuse. It is possible that some

respondents over or under-estimated the number of clients with intellectual disability and those who may have had a substance misuse problem in the previous six months.

Further Research / Next Steps

Conclusion

Large numbers of Ontario's adults with a dual diagnosis are likely in need of intensive treatment services for substance misuse problems. While there was considerable variation in how respondents viewed the relative need for enhanced services and the form those take survey respondents make a strong case for enhanced cross-sectoral collaboration in areas of training and service provision.

Recommendations

In light of the survey findings the authors make the following 3 recommendations:

#1: Evaluate the efficacy of existing substance misuse treatment services for clients with an intellectual disability.

Managers of existing treatment services within the region should undertake the above evaluation to determine if the provision of services is optimal. If required they should seek out the involvement and assistance of researchers and experts from the developmental disability sector.

#2: Further explore the relative need for enhanced services for this population.

Flowing from recommendation #1 above, should services be found either wanting in terms of effectiveness for engaging and treating clients with intellectual disability then the creation of more services may be warranted. As well, though some services are known to exist and some survey respondents have indicated their efficacy there were clearly geographic areas indicated by respondents with little or no available services. Further and pointed exploration of where the Region's citizens with intellectual disability may experience gaps in accessing substance misuse treatment services should be examined with an aim to eliminating these gaps.

#3: Develop cross-program collaborations and training amongst addictions / mental health staff and developmental services staff aimed at best ensuring treatment approaches and supports are attuned to the needs of those with intellectual disability.

The MCSS and MOHLTC have joint policy guidelines, which support such endeavours as noted in the above recommendation. As well, the MCSS has funded, through its Community Networks of Specialized Care program, positions to target health needs coordination for persons with intellectual disabilities. This coordination aim could be envisioned to include roles concerning the substance misuse treatment needs of individuals. As addictions services have in the recent past few years become integrated with mental health services agencies so should clients with intellectual disabilities benefit from closer collaboration and joint training activities across sectors.

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Appendix A: Survey Form

Substance Misuse Survey Fax / Email Form

To: Philip Burge At Fax #: 613-540-6173 ,

For questions: Phone: 613-548-5567

Today's date: _____

Your name and

Your telephone

Agency / Hospital: _____

and fax #: _____

Survey Definitions

Please read completely before answering Questions. Contact Philip Burge above if you have any questions.

Developmental disability: To have a developmental disability in Ontario one must meet criteria for significant cognitive and adaptive functioning limitations occurring before age 18 and expected to be lifelong.

For the mental health sector, this includes DSM diagnoses of "Mental Retardation" or "Autistic Disorder" (those with Aspergers and PDD NOS *do not* qualify). For DSM's 'Mental retardation' a person must meet three criteria, "subaverage general intellectual functioning that is accompanied by significant limitations in adaptive functioning... The onset must occur before age 18 years..." In recent practice, an IQ score *and* adaptive functioning assessment score of 70-75 or less are considered to meet the first two criteria.

Substance misuse: This is defined as the purposeful use of substances such as alcohol, recreational/street drugs, prescription or over the counter drugs such that the person experiences significant problems in their mental health, social relationships, living situation, health status and / or legal situation.

Survey Questions

- 1) The name of the program(s) of your agency or hospital that you are reporting for is / are?:

_____. County _____

- 2) The total number of clients estimated to be currently served by the program(s) you are reporting for (as of January 9th 2012) is: _____.

- 3) The estimated total number of these clients (as of January 9th 2012) who have a diagnosis of developmental disability or suspected developmental disability:

_____.

4) The total number of these clients with a developmental disability who also have, now or within the past 6 months, a substance misuse problem: _____.

5) Were there appropriate treatment services (e.g., 12 Step programs (NA, AA), addictions counseling) for your clients with developmental disability and substance misuse problems? (Circle one)

Yes* No**

* If Yes, please note the names of services or programs used:

*If No, please explain:

6) How would you rate the need for new or improved access to substance misuse treatment services for your clients with a developmental disability and substance misuse problems? (Circle one)

Not Needed Low Medium High Very High

7) Do you feel your agency has the capacity to work effectively with clients who have a developmental disability and are experiencing substance misuse problems? (Circle one)

Yes No

Please explain:

8) Does your agency / hospital/program provide direct treatment services for adults with developmental disability and substance misuse behaviours? (Circle one)

Yes No

9) Have you been successful in accessing these services elsewhere for your clientele with developmental disability? (Circle one)

Yes No

10) Whether or not your program provides addictions treatment services for this group,

10 a) what challenges or obstacles have your program staff experienced in providing or accessing elsewhere these services?

10 b) what factors promote success?

11) If any new substance misuse treatment services are created for persons with developmental disability to access, should they be: (Circle one)

a) Specialized developmental disability services, or

b) Wholly integrated into existing services / programs

12) May we contact you by telephone for clarifications if necessary? (Circle one)

Yes No

Other comments:

Appendix B: Acknowledgements

This study was only made possible due to the participation and assistance of many individuals. Highly appreciated was the support received from the original seven committee members of the recently formed Substance Misuse in Dual Diagnosis Committee and the Eastern Region for the Community Networks of Specialized Care (i.e., Southeastern Ontario). Committee members included the Coordinator of the CNSC Ms. Lisa Holmes and Ms. Alex Conant (Providence Care Mental Health Services), Ms. Stacey Dowling (Frontenac Community Mental Health and Addictions Services), Carole Léveillé (Health Care Facilitator, CNSC), Ms. Tania Rexe (Frontenac Community Mental Health and Addictions Services) and the authors David Williams (Lennox & Addington Addictions and Community Mental Health Services) and Philip Burge (Providence Care Mental Health Services; Queen's University).

We also thank Ms. Monica Ibrahim and Ms. Zeenah Jaffer, two former Occupational Therapy students on placement with Ms. Alex Conant's Providence Care Mental Health Services team during a portion of the time when the survey was being administered. Monica and Zeenah assisted with reminder contacts to some survey respondents, assisted a few managers complete the survey and, inputted some survey data.