USING POPULATION HEALTH SURVEYS TO MEASURE THE USE OF SERVICES AND THE PREVALENCE OF PSYCHIATRIC AND/OR BEHAVIOURAL CONDITIONS IN INDIVIDUALS WITH AN INTELLECTUAL DISABILITY

by

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ABSTRACT

Background: Compared to the general population, individuals with intellectual disabilities have a higher prevalence of health problems, including psychiatric and/or behavioural conditions (dual diagnosis). Research suggests that the proportion of persons with intellectual disabilities who have a dual diagnosis ranges from 14% to 64% depending on the population studied and the diagnostic criteria used. However, there is little population-based information in Canada about people with such a dual diagnosis.

Objectives: The aims of this study were to estimate the prevalence of psychiatric or behavioural conditions among adults with an intellectual disability in Canada, and to estimate the use of mental health services among these individuals.

Methods: This study was a secondary analysis of two cross-sectional, population-based surveys (2005 Canadian Community Health Survey: CCHS and 2006 Participation and Activity Limitation Survey: PALS), and the 2008/09 Survey of Adults with Intellectual Disabilities in South Eastern Ontario: SAID-SEO. Relevant variables were identified in the surveys to answer the study objectives. Confidence intervals were provided for all estimates and the results were compared within subgroups for each survey, as well as between surveys.

Results: The proportion of Canadian adults with an intellectual disability is 0.2% according to the CCHS and 0.5% according to the PALS. The proportion of individuals with a dual diagnosis was found to be 31% in the CCHS, 44% in the PALS, and 33% in the SAID-SEO. These prevalence estimates fall within the ranges reported in the
literature. Lastly, the majority of adults with a dual diagnosis reported using health services in the past year.

**Conclusion:** According to the three surveys examined (CCHS, PALS, SAID-SEO), psychiatric and behavioural conditions are present in about a third of the individuals with intellectual disabilities, which is in accordance with published literature. However, the estimates of the prevalence of intellectual disabilities in the CCHS and PALS were considerably lower when compared to the literature. Among the surveys, the PALS presented the highest quality of data regarding the population with a dual diagnosis. The surveys found that a majority of individuals with a dual diagnosis access some form of health services at least once a year.
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CCHS: Canadian Community Health Survey
PALS: Participation and Activity Limitation Survey
SAID-SEO: Survey of Adults with Intellectual Disabilities in South Eastern Ontario
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CCHS: Canadian Community Health Survey
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CCHS: Canadian Community Health Survey
PALS: Participation and Activity Limitation Survey
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CHAPTER 1: INTRODUCTION

1.1 Purpose

The goal of this thesis is to use existing data to derive an estimate of the proportion of adults in Canada with an intellectual disability who also have psychiatric and/or behavioural conditions, and to describe the extent to which these individuals report accessing health services for their conditions.

1.2 Background

In this chapter, background information about intellectual disability and mental illness will be presented. A section is devoted to the challenges of diagnosing psychiatric or behavioural conditions in individuals with intellectual disabilities, as well as health care utilization in this population.

1.2.1 Intellectual Disability

According to the American Association on Intellectual and Developmental Disabilities, an intellectual disability presents before the age of 18 years and is “characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills” (AAIDD, 2008). This definition of intellectual disability is accepted by Canadian mental health professionals (Griffiths, Stavrakaki & Summers, 2002). The Canadian Association for Community Living (CACL: 2008) also describes an intellectual disability as a challenge related to learning and communication that is present from birth or a young age.

In fact, most diagnostic criteria for intellectual disabilities include three crucial components: (1) intelligence that is significantly below the average (intelligence quotient
lower than 70); (2) limitations in adaptive behaviour; and (3) an origin during the developmental period (Bouras & Holt, 2007; Griffiths, Stavrakaki & Summers, 2002). As such, intellectual disabilities are developmental disabilities (National Institutes of Health, 2007). The causes of intellectual disabilities are reported to be genetic or congenital in approximately 50% of the cases (Arvio & Sillanpaa, 2003). They may also be acquired after adverse events, such as injuries during various periods of development. However, the exact causes are often unknown (Arvio & Sillanpaa, 2003).

The term ‘mental retardation’ has traditionally been the diagnostic label to describe persons with an intellectual disability, but due to its negative connotations, it has largely been replaced (Harris, 2006). Historically, terms such as mental deficiency, mental handicap, or feeblemindedness were used (Griffiths, Stavrakaki & Summers, 2002). The terms used to describe intellectual disability have differed over time due to social pressures, political agendas, and revisions of diagnostic criteria. Currently, intellectual disability can also be referred to as intellectual handicap (Davidson et al, 2003). The term ‘intellectual disability’ is used in this thesis, although articles about mentally retarded individuals will be cited in the literature review, as this term is often used to describe this population.

Intellectual disabilities affect up to 3% of the population (Roeleveld et al, 1997; Arvio & Sillanpaa, 2003). Most studies indicate that the prevalence of intellectual disabilities increases with age among children and adolescents, and is higher among males compared to females (Kirgiss et al, 2002). In Canada, it is estimated that almost 900,000 people have an intellectual disability and of these individuals, most reside in the community (CACL, 2008). However, about 30,000 Canadians with intellectual
disabilities were living in institutions in 1999 (Kaiser, 1999). Individuals living in institutions may be more physically disabled, older, or have behavioural problems (McGuigan et al, 1995).

Individuals with intellectual disabilities have a shorter life expectancy and experience more health problems compared to persons of the same sex and age (Bittles et al, 2002; van Schrojenstein Lantman de Valk et al, 1997). These include a higher incidence of sensory impairments, skin diseases, gastrointestinal problems, thyroid disorders, non-ischemic heart disease, gallbladder cancer, and dementia (van Schrojenstein Lantman de Valk et al, 1997; Jansen et al, 2004; Patja, Eero & Iivanainen, 2001; Kapell et al, 1998). Individuals with intellectual disabilities have a higher mortality rate than the general population (McGuigan et al, 1995). The prevalence of mental illness and behavioural conditions has also been reported to be higher among individuals with intellectual disabilities compared to the general population (Stromme & Diseth, 2000).

1.2.2 Psychiatric or Behavioural Conditions and Intellectual Disabilities

Persons with intellectual disabilities who have co-morbid psychiatric or behavioural conditions are considered to have a ‘dual diagnosis’ (Goldfarb & Frankel, 2007; Griffiths, Stavrakaki & Summers, 2002; Yu & Atkinson, 1993). According to A Report on Mental Illnesses in Canada (2002), mental illness is “characterized by alterations in thinking, mood or behaviour (or some combination thereof) associated with significant distress and impaired functioning” (Public Health Agency of Canada, 2002, pg. 7). In psychiatry, mental illness refers to a spectrum of conditions classified by psychiatric or behavioural disorders that are clinically meaningful and result in
significant distress or disability for the individual (Livingston-Bruce, 1999; American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, 2000).

In the field of intellectual disabilities, mental illness presentation is sometimes referred to as challenging behaviour (Centre for Developmental Disability Health: CDDH, 2005). Challenging behaviour was first used to describe problem behaviour among individuals with intellectual disabilities during the 1980s in North America (Xeniditis, Russell & Murphy, 2001). Challenging behaviour is commonly defined as behaviour of intensity, frequency, or duration that affects the safety of the individual or threatens the people around the individual, or behaviour that limits or does not allow the individual to utilize community facilities (CDDH, 2005). Challenging behaviour may be caused by medical or psychiatric problems, or may be a response to environmental factors, such as discomfort, inability to communicate, major life events, or side-effects of medication. It may present as aggression, self-injurious behaviour, non-compliant behaviour, socially inappropriate behaviour, or withdrawal. Challenging behaviour may be a threat to the individual or others, and it must be managed as it can result in a series of complications, such as injury or a lower quality of life (CDDH, 2005). Problem behaviours present great difficulties for not only the client, but also for caretakers, such as family members or staff (Freedman & Chassler, 2004).

It is important to consider both psychiatric and behavioural conditions among individuals with an intellectual disability, as both disorders often co-exist (Xeniditis, Russell & Murphy, 2001). One study which investigated the relationship between psychiatric and behavioural conditions among individuals with intellectual disabilities was done in South Eastern Ontario using data from the Geographic Registry in
Intellectual Disabilities (GRID: Ouellette-Kuntz et al, 2007a). The results showed that 25% of the individuals had a psychiatric condition, while 26% had a behaviour problem. However, 14% of the individuals presented with both conditions.

In a review article by Kerker et al (2004), the authors describe various risk factors which may contribute to the higher prevalence of mental illness among individuals with intellectual disabilities. Biochemical irregularities due to brain damage or genetic abnormalities may be linked to some psychiatric symptoms or problem behaviours (Kerker et al, 2004; Cooper & Bailey, 2001). In addition, psychological and social factors, such as reduced social acceptance and stigma, can lead to mental health problems in individuals with intellectual disabilities (Kerker et al, 2004; Cooper & Bailey, 2001). Social disadvantages, the unavailability of services, unemployment, and poverty also contribute to psychopathology among people with intellectual disabilities (Cooper & Bailey, 2001; Kerker et al, 2004; Taylor et al, 2004).

Figure 1 provides an overview of the terms that will be used in the thesis and how they are related to each other.

*Figure 1. Relationship among Terms Used in Thesis*

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<th>DUAL DIAGNOSIS</th>
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<td>Behavioural Conditions</td>
<td>Challenging Behaviour</td>
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1.2.3 Diagnosing Psychiatric or Behavioural Conditions

Diagnosing psychiatric and behavioural conditions in individuals with an intellectual disability may be challenging because the presentation of symptoms in this population may differ from that found in diagnostic criteria manuals, such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) or the International Classification of Diseases (ICD) (Bouras & Holt, 2007; Campbell & Malone, 1991). The two main problems with diagnosing disorders in this population are the challenges of using existing diagnostic criteria and the lack of specialty training among mental health professionals.

Firstly, most diagnostic criteria may not be suitable for use with individuals with intellectual disabilities, as these individuals may lack the ability to describe their symptoms. The appropriateness of mental illness diagnostic criteria for adults with intellectual disabilities is often dependent on the level of functioning of the individual (Bouras & Holt, 2007). Consequently, clinicians and researchers have attempted to create diagnostic manuals that reflect the presentation of mental illnesses in individuals who have intellectual disabilities. Such examples include the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities in Britain (Bouras & Holt, 2007), but these diagnostic criteria are not widely used in Canada. Additionally, assessment tools for measuring the symptoms of psychopathology in individuals with intellectual disabilities, such as the Reiss Screen for Maladaptive Behavior (RSMB) and the Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD Checklist), have been developed and tested to be reliable in diagnosing mental illness in this population (Moss et al, 1998; Reiss, 1988; Sturmey & Bertman 1994; Sturmey, Burcham & Perkins, 1995).
Secondly, the other barrier to diagnosing psychiatric illnesses in individuals with intellectual disabilities is the limited number of psychiatrists and mental health staff trained and specialized in this field (Lunsky et al, 2006; Freedman & Chassler, 2004). Psychiatry residents in Canada report a scarcity of specialty training in intellectual disabilities in their residency programs (Burge et al, 2002). Greater physician and mental health staff training is required, as are specialized mental health services, defined as “clinical services that utilize a biopsychosocial approach and focus on informed practices” (Lunsky et al, 2007; Community Networks of Specialized Care: CNSC, 2007).

Fortunately, considerable effort has been made in recent years to improve the services for individuals with a dual diagnosis. In 2006, the Ministry of Community and Social Services in Ontario established four Community Networks of Specialized Care to support the provision of services to individuals with a dual diagnosis that are accessible, coordinated, and integrated (CNSC, 2007). Groups such as the recently formed National Coalition on Dual Diagnosis are advocating for greater awareness of individuals with a dual diagnosis within the National Mental Health Strategy (National Coalition on Dual Diagnosis, 2008). These services and advocacy groups may improve access to mental health care for those with a dual diagnosis.

1.2.4 Mental Health Care Utilization among Adults with Intellectual Disabilities

An Ontario-based study found that a third of hospital admissions among individuals with an intellectual disability are for mental illnesses (Balogh, Hunter & Ouellette-Kuntz, 2005). Another study found that this population had a significantly longer length of hospital stay for psychiatric admissions compared to adults without an intellectual disability (Saeed et al, 2003). Individuals with psychiatric or behavioural
conditions require specialized mental health care as their needs differ from those of the general population (Cooper, Melville & Morrison, 2004). Patients with a dual diagnosis often present with more severe mental illness and a higher level of psychiatric care is necessary (Lunsky et al, 2006). Despite this, some authors have found that psychiatric care utilization is lower among individuals with a dual diagnosis when compared to the general population (Gustafsson, 1997). In an English study, it was found that only around 37% of the individuals with intellectual disabilities who reported having mental health problems were receiving psychiatric services, leading the authors to note that an unmet need existed among this population (Martin, Roy & Wells, 1997).

Similarly, a follow-up study of individuals with intellectual disabilities found that over 60% of those with challenging behaviour problems as children and adolescents had no specialist care from mental health professionals as adults, although these individuals were in contact with primary care providers (McCarthy & Boyd, 2002). The authors mentioned that this could have happened due to a lack of mental health professionals trained in the care of individuals with intellectual disabilities. Likewise, a review article done by Chaplin (2004) showed that professionals providing general care felt that they did not have adequate training to treat people with intellectual disabilities and that these individuals did not have good access to primary care services.

1.3 Rationale

Mental illness affects 20% of Canadians during their lifetime (Public Health Agency of Canada, 2002), while the prevalence rates among individuals with intellectual disabilities are estimated to be higher (Stromme & Diseth, 2000). Mental illness is related to greater health service utilization and worse health-related quality of life compared to
the general population (Lim et al, 2008). In addition, the health care costs related to psychiatric and behavioural conditions are substantial. The economic burden of mental illness among the Canadian population was valued at $51 billion in 2003 (Lim et al, 2008). In the Netherlands, health care costs associated with any psychiatric or behavioural diagnoses account for over 20% of the health care budget (Meerding et al, 1998). In addition, the treatment costs of individuals diagnosed with mental retardation accounted for 8% of the health care costs (Meerding et al, 1998).

Bradley et al (2002) mention that an “understanding of prevalence patterns permit[s] more rational planning of services and targeting of resources” (p.653). In order to appropriately provide specialized mental health care to individuals with intellectual disabilities and co-morbid psychiatric or behavioural conditions, the proportion of individuals with a dual diagnosis residing in the community needs to be known.

However, there is little population-based information in Canada about these individuals. The major national reports on mental health, such as the Public Health Agency of Canada’s A Report on Mental Illnesses in Canada (2002) and The Human Face of Mental Health and Mental Illness in Canada (2006), do not specifically address the problem of mental ill-health in individuals with intellectual disabilities. Additionally, no Canadian studies investigating dual diagnoses in community-based populations have been identified in the literature review presented in the next chapter (Chapter 2). In summary, dual diagnosis is a significant concern for government and service providers due to numerous reasons, such as the limited body of knowledge about this population in Canada, significant health care costs associated with treating individuals with a dual
diagnosis, and the need for specialized health services to treat mental illness in this population.

National health surveys are often used for analyzing trends in the occurrence of various health conditions among the Canadian population. Two surveys (Canadian Community Health Survey and Participation and Activity Limitation Survey) pose relevant questions that may be used to gain more information about the dual diagnosis population in Canada. The feasibility of using these national surveys to determine the proportion of individuals with intellectual disabilities who have a dual diagnosis and health care utilization among this population has not, however, been reported.
CHAPTER 2: PREVALENCE OF DUAL DIAGNOSIS

2.1 Dual Diagnosis Prevalence in Literature

It is generally reported that individuals with intellectual disabilities have a higher prevalence of psychiatric and behavioural conditions compared to the general public, yet no review of population-based studies investigating this topic was identified. Therefore, the purpose of this chapter is to critically evaluate the available literature and determine the proportion of persons with an intellectual disability who have a dual diagnosis among individuals living in the community.

2.2 Literature Search Methodology

The National Health Service Centre for Reviews and Dissemination (NHS CRD, 2001) guidelines were followed for the review of population-based studies investigating the proportion of dual diagnosis among those with an intellectual disability. The following databases were searched by a single reviewer using database specific search terminology: OVID Medline, OVID Healthstar, PsycINFO, CINAHL, EMBASE, Global Health, AMED, and All EBM Reviews – Cochrane DSR, ACP Journal Club, DARE, and CCTR. A list of database specific search terminology and search dates is found in Appendix A. Most databases were searched between the years of 1980 and 2008. These dates were chosen for the review because a preliminary examination of the literature showed that numerous studies were published during this time period. The year 1980 also coincides with the publication of the third edition of the Diagnostic and Statistical Manual of Mental Disorders and an increased focus on moving individuals with intellectual disabilities from institution-based residential settings to community living (Griffiths, Stavrakaki & Summers, 2002).
Population-based studies in the English or French language on the prevalence of psychiatric or behavioural conditions among individuals 16 years of age or older with intellectual disabilities were included. As the thesis is examining dual diagnosis among adults, studies about individuals who were 18 years of age or older were initially considered. However, with the identification of high-quality studies which included younger individuals in the research, the age was revised to 16 years of age or older. Studies that described a single condition leading to an intellectual disability, for example, Down Syndrome, or that assessed a specific psychiatric or behavioural condition were excluded. Studies that presented an overall prevalence of psychiatric or behavioural conditions were included in the review. Only primary research that focused on the whole population of individuals with intellectual disabilities in a community was included.

The titles and abstracts of all identified studies were screened by one reviewer to ensure that the studies met eligibility criteria. Publications that described studies assessing psychiatric and/or behavioural conditions among individuals with an intellectual disability were included for review. The selected full-text articles were then screened by a single reviewer based on eligibility criteria. The reference lists of the articles were hand-searched to identify any additional articles meeting eligibility criteria.

Grey literature was identified through Google and Google Scholar searches. For the Google search, the first 50 identified websites were searched for reports that looked at dual diagnosis. For the Google Scholar search, the first 50 articles were assessed for inclusion in the review, as these entries were the most relevant to the search criteria.

The chosen articles were assessed for quality based on the representativeness of the sample to the underlying population and whether the validity of the measurement tool
and/or approach used to identify psychiatric or behavioural conditions were reported. These two factors were assessed as present (‘yes’), absent (‘no’), or ‘unclear’, and a decision was made between two reviewers whether to include the study in the review. Any disagreements were resolved through consensus. The form used for data quality assessment is found in Appendix B. Data from the full-text articles were extracted by two reviewers using a data extraction and quality assessment form (found in Appendix C).

In total, 15,677 articles were identified (Figure 2). After applying the inclusion and exclusion criteria to the titles and then to the abstracts, 424 articles remained. After the removal of duplicate studies, 98 full-text articles were obtained. From these, 21 articles describing dual diagnosis were selected for the review. One additional article was identified through a search of citations. No grey literature was identified. Overall, the 22 articles described 21 population-based studies (see Appendix D for reference list).

Figure 2. Systematic Review Process

15,677 articles found

1,421 articles after inclusion/exclusion criteria applied to titles

424 articles after inclusion/exclusion criteria applied to abstracts

98 articles after removal of duplicates

21 articles chosen

+1 from citation

22 articles in review
2.3 Identifying Dual Diagnosis

As mentioned in Chapter 1, there are many challenges to diagnosing psychiatric and behavioural conditions among individuals with intellectual disabilities, including using diagnostic criteria specifically designed for use with this population. Although various assessment tools exist, there is a lack of agreement in terms of appropriate standards for diagnosing mental illness among individuals with intellectual disabilities (Moss et al., 1993). Diagnosing mental health problems is further complicated if it is unclear if the symptoms are part of the intellectual disability or an indication of a mental health problem. In 1994, Reiss proposed that diagnostic overshadowing may lower the true prevalence of dual diagnosis due to psychiatric and behavioural symptoms being assessed as presentations of the intellectual disability (Bouras & Holt, 2007). In addition, the identification of these problems may be difficult due to a communication barrier that often exists among individuals with severe intellectual disabilities. It is important that carers and family members of individuals with intellectual disability be aware of the varied presentations of psychiatric and behavioural conditions among this population (Moss et al., 1993, Moss et al., 1998).

As mentioned in Chapter 1, psychiatric and behavioural conditions are often co-morbid in individuals with intellectual disabilities and should both be considered in the definition of dual diagnosis. The prevalence of psychiatric and behavioural conditions ranges depending on the diagnostic criteria used, as was shown in an article by Cooper et al. (2007). The prevalence estimates of dual diagnosis in the literature are provided in the next section, grouped by psychiatric or behavioural disorders.
Standardized assessment and screening tools are available to measure the presence and severity of symptoms of mental illness (Bouras & Holt, 2007). Their goal is to ensure that the method of categorizing symptoms and establishing a diagnosis is done in an objective manner that is valid and reliable. Several standardized assessment and screening tools have been developed for the population with intellectual disabilities. Certain tools are administered by qualified mental health professionals, while others may be completed by proxy respondents who may or may not be trained in this field of mental health.

Criteria provided by diagnostic manuals may also be utilized in studies. This method is commonly used by physicians for diagnostic purposes. The manuals group patient symptoms into syndromes and describe various mental illnesses (Bolton, 2007). The diagnostic manuals have been developed to provide standardized classification of symptoms and diagnoses based on consensus of professional bodies.

Psychopathology among individuals with intellectual disability can be assessed through the use of various surveys of developmental service recipients or their caregivers. These surveys are not always tested to be valid and reliable in identifying individuals diagnosed as having a mental illness.

Lastly, certain studies use administrative databases to determine the prevalence of psychiatric and behavioural conditions. The data are often extracted from registers from agencies that provide services for individuals with intellectual disabilities. However, the information contained in these databases is collected for administrative purposes so it may have been inputted by numerous individuals and may not be verifiable (Statistics Canada, 2003). Registers of individuals with intellectual disabilities are not as common in
Canada and the United States as they are in European countries (Bradley et al, 2002). As such, prevalence studies must rely on individuals identified through service agencies. This has been dubbed as service prevalence. These studies therefore exclude individuals who do not receive services. While the prevalence of severe intellectual disabilities is assumed to be close to the true prevalence as these individuals are likely to be receiving services for their condition, many with milder disabilities may be unknown to the service system particularly once they leave the education system (Bradley et al, 2002).

In order to make sense of the variations in study results, the estimates derived from the chosen studies are further divided by the diagnostic methods used, including standardized assessments, criteria provided by diagnostic manuals, surveys of service recipients, and administrative databases (for psychiatric conditions only).

Where reported, the association between the level of intellectual disability and mental illness is also presented. The chapter concludes with a summary of the implications of the findings for understanding the prevalence of psychiatric and behavioural conditions among Canadians with intellectual disabilities.

2.4 Psychiatric Conditions

Seventeen studies were identified that described psychiatric disorders. Some of the articles provided combined prevalence estimates of psychiatric disorders and behaviour disorders. Four of the studies based diagnosis on criteria provided in diagnostic manuals, while six studies used standardized assessments to diagnose psychiatric conditions. Surveys of developmental service recipients or their caregivers examined the proportion of individuals with a dual diagnosis in four studies. The remaining three studies used administrative databases to arrive at the prevalence of
psychiatric disorders. The study results for behavioural conditions are presented in a similar manner in Section 2.5.

2.4.1 Criteria Provided by Diagnostic Manuals

Four studies in which psychiatric conditions among individuals with intellectual disabilities were diagnosed based on criteria published by international bodies were identified. Mental health professionals and researchers have worked to modify these manuals to adapt diagnostic criteria to assess psychopathology in individuals with intellectual disabilities. The earliest identified study since 1980 to use published diagnostic criteria to diagnose psychiatric conditions among individuals with intellectual disabilities was done by Gostason (1985). This author did a population census of individuals with intellectual disabilities in Kopparberg County, Sweden. Overall, 122 individuals residing in the community were interviewed by a psychiatrist and diagnosed according to the DSM-III criteria (APA, 1980). The author found that 43% of the population with intellectual disabilities had at least one DSM-III diagnosis.

A more recent study done by Cooper et al (2007) found a similar prevalence estimate based on clinical assessments done by psychiatrists working with individuals with intellectual disabilities. The authors also used three other diagnostic criteria to investigate the prevalence of psychiatric conditions. In the study, individuals who were 16 years and over were identified through health service agencies from the Greater Glasgow Health Board area of Scotland. Among the 1023 study participants, the point prevalence of mental illness was 41% based on clinical assessments, 35% using the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD: Royal College of Psychiatrists, 2001), 17%
using the International Classification of Disease, 10th revision, Diagnostic Criteria for Research (ICD-10-DCR: World Health Organization, 1993), and 16% based on the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (Text Revision) (DSM-IV-TR: APA, 2001). The authors indicated that the prevalence estimates based on the ICD-10-DCR and DSM-IV-TR criteria were lower compared to the other diagnostic methods due to the ICD-10-DCR and DSM-IV-TR criteria not accurately portraying the presentation of psychiatric disorders in individuals with intellectual disabilities.

Clay and Thomas (2005) also used the DSM-IV-TR diagnostic criteria in their study, although they found a higher prevalence of dual diagnosis. They did a retrospective chart review of a stratified random sample of files of clients receiving services through Marion County Developmental Disabilities in Oregon, USA. In total, 179 files were assessed for a diagnosis of Axis I psychopathology based on testing done by psychologists and classified according to the DSM-IV-TR. The prevalence of Axis I psychopathology was 31%. The authors could not verify the diagnoses as they only had access to the health records of the patients.

A similar prevalence estimate to this one was found by Bhaumik et al (2008) using the ICD-10 diagnostic criteria (WHO, 1992). A cross-sectional study of all adults with intellectual disabilities identified through specialist psychiatric services in Leicestershire and Rutland, UK, was undertaken. In total, 2711 individuals 19 years and over participated. The participants were assessed by a consultant psychiatrist and diagnosed according to ICD-10 criteria. Overall, 34% of the individuals had a psychiatric disorder, including behaviour disorders.
As shown in Table 1, even when relying on published diagnostic criteria, estimates of the occurrence of psychopathology among individuals with intellectual disabilities vary greatly. The prevalence is most commonly reported to be between 31% and 43%. The two outliers (ICD-10-DCR and DSM-IV-TR) have been addressed earlier in the text. It is important to note though that the authors of this study arrived at higher prevalence estimates on the same population through a clinical assessment and using the DC-LD.

**Table 1. Results for Psychiatric Conditions by Diagnostic Manual**

<table>
<thead>
<tr>
<th>Study</th>
<th>Diagnostic Tool</th>
<th>Sample Size</th>
<th>Prevalence Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gostason (1985)</td>
<td>DSM-III</td>
<td>122</td>
<td>43%</td>
</tr>
<tr>
<td>Cooper <em>et al</em> (2007)</td>
<td>Clinical assessment</td>
<td>1,023</td>
<td>41%</td>
</tr>
<tr>
<td></td>
<td>DC-LD</td>
<td>1,023</td>
<td>35%</td>
</tr>
<tr>
<td></td>
<td>ICD-10-DCR</td>
<td>1,023</td>
<td>17%</td>
</tr>
<tr>
<td></td>
<td>DSM-IV-TR</td>
<td>1,023</td>
<td>16%</td>
</tr>
<tr>
<td>Clay &amp; Thomas (2005)</td>
<td>DSM-IV-TR</td>
<td>179</td>
<td>31%</td>
</tr>
<tr>
<td>Bhaumik <em>et al</em> (2008)</td>
<td>ICD-10</td>
<td>2,711</td>
<td>34%</td>
</tr>
</tbody>
</table>

Using diagnostic manuals for research may be challenging due to the need of assessments being performed by qualified mental health professionals. On the other hand, diagnoses based on these criteria can be used in research through a review of medical or social service records, as was done by Clay and Thomas (2005). This leads into the next section in which psychopathology is assessed through standardized assessment tools.

### 2.4.2 Standardized Assessments

Standardized assessment tools have been developed to be used to screen for or diagnose psychiatric conditions in individuals with intellectual disabilities. In studies using such approaches, caregivers of individuals with intellectual disabilities most commonly complete these questionnaires. The included studies used five different tools: the Psychopathology Instrument for Mentally Retarded Adults (PIMRA), the Reiss
Screen for Maladaptive Behavior (RSMB), the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) and Mini PAS-ADD, and the Diagnostic Assessment for the Severely Handicapped (DASH).

The Psychopathology Instrument for Mentally Retarded Adults (PIMRA) is based on the DSM-III (Senatore, Matson & Kazdin, 1985; Matson, 1988). The PIMRA is used for diagnostic purposes. The PIMRA is completed by caregivers of individuals with an intellectual disability and it is centred on 56 items to which the respondent answers ‘yes’ or ‘no’. Psychiatric problems are present when an individual scores positive on four or more of the seven items found in the sub-scales. The individual is classified as having a mental illness if he or she has a positive score on one of the sub-scales. However, the assessment tool’s validity in diagnosing psychiatric disorders in individuals with severe intellectual disability has not been assessed (Gustafsson & Sonnander, 2004).

The PIMRA was used to examine dual diagnosis in an American study during the 1980s (Iverson & Fox, 1989). Using the Waukesha County Community Service annual report data, the researchers identified all individuals with mental retardation aged 21 years and over who were receiving services. The authors selected a random stratified sample of 165 individuals. Based on the results, 36% of the sample was found to have a presence of psychopathology. The authors found no difference by sex, age category, or living environment. However, there was a statistically significant difference between level of mental retardation and psychopathology. Individuals with mild mental retardation had the highest proportion of dual diagnosis at 55%, compared to 32% of moderately and 26% of severely or profoundly mentally retarded individuals.
Another study which employed the PIMRA to assess psychopathology was done by Matthews et al (2008). The authors studied 318 participants with intellectual disabilities, 17 years or older, from general practices in South and Mid Wales. Overall, 46% of the individuals had positive scores. The authors investigated the prevalence of psychopathology among individuals with and without seizures, but did not find statistically significant differences. Compared to the study by Iverson and Fox (1989), the sample was not selected at random but rather, the general practices nominated the clients. The authors acknowledged that the sample did not represent the underlying population with intellectual disabilities with regards to all characteristics, although age and place of residence were similar.

Gustafsson and Sonnander (2004) also used the PIMRA to assess psychopathology among individuals with an intellectual disability in a Swedish county. In contrast to the other studies, the authors found a much higher prevalence of psychiatric conditions among the 124 individuals assessed. The authors found that 64% of the sample scored positive for psychopathology. These researchers also had the Reiss Screen for Maladaptive Behavior (RSMB: Reiss, 1988) completed for each individual in their study. The RSMB was designed for screening purposes and the maladaptive behaviours in the tool are not based on diagnostic criteria provided by manuals. There are 38 items in the tool, which are usually completed by two people familiar with the individual using three options: ‘no problem’, ‘a problem’, or ‘a major problem’. Of the participants, 41% scored nine or more points on the 26-item score, indicating the presence of psychopathology.

Additionally, the authors used the RSMB to assess individuals with intellectual disabilities in another Swedish county with a sample of 134 individuals. Of the
participants, 34% scored positive, indicating the presence of psychopathology. Compared to the other county, the prevalence estimate was lower although the statistical significance of the difference between the results was not addressed. The authors noted that compared to individuals with mild intellectual disability in the combined samples, those with severe intellectual disabilities had significantly higher results on some of the subscale scores of the RSMB, such as the aggression and autism subscales.

The authors indicated that the difference in the prevalence estimates of dual diagnosis found with the PIMRA and RSMB could be due to how the assessment tools were administered (Gustafsson & Sonnander, 2004). The RSMB was based on the average scores of two staff members who completed a self-administered form, while the PIMRA was completed through staff interviews. The authors also noted that the PIMRA is used for diagnostic purposes, while the RSMB is a screening tool for maladaptive behaviours.

Another standardized assessment tool used is the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD: Moss et al, 1993), as well as the Mini PAS-ADD (Prosser et al, 1998), which are based on ICD-10 criteria. Three subscales are present in the PAS-ADD and these are: affective/neurotic disorder, possible organic condition, and psychotic disorders. Psychopathology is identified when the participant scores at or above the threshold scores suggested. The Mini PAS-ADD generates seven subscale scores. The questionnaire is completed through a face-to-face interview with the individual and their caregiver. The Mini PAS-ADD and PAS-ADD were used in a study in Vale of Glamorgan, South Wales, UK (Deb, Thomas & Bright, 2001a). In total, 120 people, 16 years and over, were sampled through a computerized
randomization of 246 individuals, and 101 people completed the study. Of these participants, 90 individuals had a mild or moderate intellectual disability and their communication abilities allowed for the completion of both the Mini PAS-ADD and the PAS-ADD. Based on the Mini PAS-ADD, 22% of these individuals had a psychiatric diagnosis. Based on the PAS-ADD, 14% (95% CI: 7-21%) of the individuals had a psychiatric illness.

Taylor et al (2004) found a prevalence of psychopathology similar to that of Deb, Thomas and Bright (2001a). The authors investigated the prevalence of psychiatric conditions among 1155 individuals with intellectual disabilities, 17 years and over, living in Northeast England. Using the PAS-ADD Checklist, 20% of the sample scored positive for a mental health problem.

The results presented by the previous two authors are lower than those reported by other researchers. Holden and Gitlesen (2004) selected a sample of 96 individuals (18 years of age and over) from a population of people with intellectual disabilities receiving services from health service providers in the county of Hedmark, Norway. Using the Mini PAS-ADD, the authors found that the prevalence of one or more psychiatric disorders among the sample was 33%.

Deb, Thomas and Bright (2001a) used the Diagnostic Assessment for the Severely Handicapped (DASH: Matson et al, 1991) to assess psychopathology among the remaining 11 participants who lacked sufficient communication abilities to complete the PAS-ADD in the study previously described. The DASH indicated that 18% of the individuals with severe intellectual disabilities had a psychiatric diagnosis, although the authors acknowledged that the sample size was small (n=11).
As can be seen in Table 2, the prevalence of psychiatric conditions is most commonly reported to be 33% to 46%. This is similar to the range of prevalence estimates described using diagnostic assessment tools. The highest prevalence is reported in the study by Gustafsson and Sonnander (2004), where the prevalence of psychopathology was reported to be 64% based on the PIMRA. However, the same sample had an almost 25% lower prevalence of maladaptive behaviours when screened by the RSMB, indicating that the assessment tool accounted for the difference in prevalence estimates of psychopathology.

<table>
<thead>
<tr>
<th>Study</th>
<th>Diagnostic Tool</th>
<th>Sample Size</th>
<th>Prevalence Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iverson &amp; Fox (1989)</td>
<td>PIMRA</td>
<td>165</td>
<td>36%</td>
</tr>
<tr>
<td>Matthews et al (2008)</td>
<td>PIMRA</td>
<td>318</td>
<td>46%</td>
</tr>
<tr>
<td>Gustafsson &amp; Sonnander (2004)</td>
<td>PIMRA</td>
<td>124</td>
<td>64%</td>
</tr>
<tr>
<td></td>
<td>RSMB – Sample 1</td>
<td>124</td>
<td>41%</td>
</tr>
<tr>
<td></td>
<td>RSMB – Sample 2</td>
<td>134</td>
<td>34%</td>
</tr>
<tr>
<td>Deb, Thomas &amp; Bright (2001a)</td>
<td>Mini PAS-ADD</td>
<td>90</td>
<td>22%</td>
</tr>
<tr>
<td>Holden &amp; Gitlesen (2001)</td>
<td>Mini PAS-ADD</td>
<td>96</td>
<td>33%</td>
</tr>
<tr>
<td>Deb, Thomas &amp; Bright (2001a)</td>
<td>PAS-ADD</td>
<td>90</td>
<td>14% (7%-21%)*</td>
</tr>
<tr>
<td>Taylor et al (2004)</td>
<td>PAS-ADD</td>
<td>1,155</td>
<td>20%</td>
</tr>
<tr>
<td>Deb, Thomas &amp; Bright (2001a)</td>
<td>DASH</td>
<td>11</td>
<td>10%</td>
</tr>
</tbody>
</table>

*The other studies did not present a 95% confidence interval

A discrepancy exists between the prevalence estimates given by different tools. This variation may be due to the difference in levels of intellectual disability of the samples. For example, the study by Deb, Thomas and Bright (2001a) excluded individuals with severe and profound intellectual disabilities when applying the Mini PAS-ADD. Conversely, Holden and Gitlesen (2001) excluded individuals with mild intellectual disabilities and the sample size was almost evenly distributed between those with moderate, severe, or profound disabilities. Lastly, only the study by Deb, Thomas and Bright (2001a) reported 95% confidence intervals and due to this, it is possible to determine that the prevalence estimates of psychopathology assessed by the PAS-ADD
do not differ from those in the study by Taylor *et al* (2004). However, it is emphasized that standardized assessment tools should not be a substitute for a comprehensive assessment of psychopathology completed by a team of mental health professionals (Bouras & Holt, 2007).

The prevalence of psychiatric conditions among those with intellectual disabilities will next be compared to the prevalence found through surveys of service recipients.

### 2.4.3 Surveys of Service Recipients

Four studies surveyed service recipients and their caregivers. Psychopathology was assessed this way among those with an intellectual disability in Aarhus County, Denmark (Lund, 1985). Individuals 20 years and over were selected using two-stage cluster sampling from the Danish National Service for the Mentally Retarded register. Of the 324 individuals selected, 302 participated in the study. The Medical Research Council - Schedule of Handicaps, Behaviour, and Skills (MRC-HBS: Wing, 1980), as well as a schedule of psychiatric symptoms prepared for the study, were used to assess psychopathology according to DSM-III criteria. Overall, the prevalence estimate for having one or more psychiatric disorders was 28%.

A similar prevalence of dual diagnosis to that found by Lund (1985) was found by Lowe *et al* (2007). In a study investigating behaviour problems, the authors noted the prevalence of psychiatric disorders among 705 individuals, 19 years and older, from South Wales, UK. The prevalence of psychiatric disorders was 28%, although no specific diagnostic criteria were indicated to have been used in the article.

Similarly, a comparable prevalence estimate to that noted above was found in a large survey of individuals with intellectual disabilities receiving services in six
American states (Massachusetts, Indiana, Kentucky, Alabama, Oklahoma, and Wyoming) (Lakin et al., 2007). Overall, 2720 individuals (over 90% response rate) were interviewed using the National Core Indicators (NCI) Consumer Survey of developmental service recipients and key informants (Human Services Research Institute, 2001). Of these individuals, 31% were reported to have a psychiatric disorder.

The lowest prevalence of psychiatric disorders derived from surveys was found by Freedman and Chassler (2004). A sample of 1192 individuals, 18 years and over, were randomly chosen for the study from the Massachusetts Department of Mental Retardation (DMR) Consumer Registry System. Of these individuals, 629 participated. Data on the presence of psychiatric conditions were collected using the DMR Consumer Survey instrument designed specifically for departmental use by the Human Services Research Institute (2001). Based on the proxy responses, 15% of the sample had a mental illness or psychiatric diagnosis.

Table 3 shows the summary of results for the prevalence of dual diagnosis estimated through proxy response surveys. As can be seen, the prevalence of dual diagnosis is most commonly reported as being between 28% and 31% based on these studies. This is in line with the previous two assessment methods discussed earlier. However, the study by Freedman and Chassler (2004) reported a dual diagnosis prevalence of 15%. This prevalence estimate is lower than those mentioned before, which could be due to the low participation rate (58%) in the study.

Table 3. Results for Psychiatric Conditions by Survey of Service Recipients

<table>
<thead>
<tr>
<th>Study</th>
<th>Diagnostic Tool</th>
<th>Sample Size</th>
<th>Prevalence Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lund (1985)</td>
<td>MRC-HBS, schedule of psychiatric symptoms</td>
<td>302</td>
<td>28%</td>
</tr>
<tr>
<td>Lowe et al (2007)</td>
<td>Criteria not indicated</td>
<td>705</td>
<td>28%</td>
</tr>
<tr>
<td>Lakin et al (2007)</td>
<td>NCI Consumer Survey</td>
<td>2,720</td>
<td>31%</td>
</tr>
<tr>
<td>Freedman &amp; Chassler (2004)</td>
<td>DMR Consumer Survey</td>
<td>629</td>
<td>15%</td>
</tr>
</tbody>
</table>
2.4.4 Administrative Data

Three studies investigated psychiatric disorders among those with intellectual disabilities through administrative data. Using probabilistic matching, researchers in Western Australia cross-linked population-based intellectual disability and psychiatric registers, containing ICD-9 coded diagnoses (Morgan et al., 2008; WHO, 1978). The resulting database contained records for 13,295 individuals with intellectual disabilities who were 23 to 52 years old. The authors found that 32% of the individuals had a psychiatric disorder diagnosis.

Another study which used psychiatric diagnoses coded according to the ICD-9 included everyone with an intellectual or developmental disability receiving services or supports in New York State using the New York State Office of Mental Retardation and Developmental Disabilities register (Davidson et al., 2003). Overall, 60,752 individuals who were 21 years and older were identified. Data about psychiatric diagnoses were captured using the Developmental Disabilities Profile-Form 2, which contains psychiatric diagnoses using ICD-9 categories recorded in the database by medical professionals or service coordinators. The authors indicated that the diagnoses could not be validated. Of the population, 23% were reported to have a psychiatric diagnosis.

An earlier study also from New York State found a lower prevalence estimate. Using the New York Developmental Disabilities Information System, Jacobson (1982) investigated the prevalence of psychiatric conditions among 25,766 developmental service recipients. Based on the data, 14% of the population had a dual diagnosis (Jacobson, 1982).

The results for this section are presented in Table 4. As can be seen, the more recent studies have a higher prevalence of psychiatric illness. The study published in
1982 could have a lower prevalence of dual diagnosis due to a lower quality of data that were recorded in the database or a different clientele that was served in New York State, as compared to the newer study by Davidson *et al* (2003). These population-based studies provide information on the overall prevalence of dual diagnosis, but caution must be taken when analyzing the prevalence estimates as the authors of the studies were not able to validate the diagnoses found in the databases.

*Table 4. Results for Psychiatric Conditions by Administrative Database*

<table>
<thead>
<tr>
<th>Study</th>
<th>Diagnostic Tool</th>
<th>Sample Size</th>
<th>Prevalence Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morgan <em>et al</em> (2008)</td>
<td>Western Australia database</td>
<td>13,295</td>
<td>32%</td>
</tr>
<tr>
<td>Davidson <em>et al</em> (2003)</td>
<td>New York State database</td>
<td>60,752</td>
<td>23%</td>
</tr>
</tbody>
</table>

### 2.5 Behavioural Conditions

There were eleven studies that assessed behavioural conditions among individuals with intellectual disabilities. Behavioural conditions were defined differently in most studies, based on the methods used to assess the presence of the conditions. The definition of behavioural condition is described alongside the study. Three studies used diagnostic manuals to assess behavioural disorders. Three additional studies used assessment tools to diagnose behaviour disorders, while five studies surveyed service recipients and their caregivers to determine whether behaviour problems existed. None of the studies used large population-based databases.

#### 2.5.1 Criteria Provided by Diagnostic Manuals

Three studies assessed behavioural conditions among individuals with intellectual disabilities using diagnostic manuals. One such study was done by Cooper *et al* (2007). The authors used four sets of published diagnostic criteria to assess behavioural conditions. A diagnosis of behaviour problems was found in 19% based on DC-LD
criteria, 0.1% based on ICD-10-DCR criteria, and 0.1% based on DSM-IV-TR criteria. In contrast, 23% of the individuals were considered to have a behaviour problem based on clinical assessment by a psychiatrist with experience in dual diagnosis. The prevalence estimates using the ICD-10-DCR and DSM-IV-TR criteria are markedly lower compared to the other diagnostic methods, which may be due to the inability of these diagnostic manuals to accurately classify behaviour disorders among those with intellectual disabilities (Cooper et al., 2007).

However, this does not explain the discrepancy found between the prevalence estimate reported in 2001 by Cooper and Bailey also using the ICD-10-DCR. The study (described earlier) indicated that 15% of the individuals had a behaviour disorder. This prevalence estimate is similar to that found using ICD-10 criteria in another study. The previously mentioned cross-sectional study by Bhaumik et al. (2008) found that 20% of the individuals with intellectual disabilities in Leicestershire and Rutland, UK, had a behaviour disorder according to ICD-10 criteria.

The results from this section are summarized in Table 5. As can be seen, the prevalence estimates of behavioural conditions most commonly reported are between 15% and 23%. However, there are two outliers which are likely due to the inapplicability of the diagnostic criteria to individuals with intellectual disabilities.

Table 5. Results for Behavioural Conditions by Diagnostic Manual

<table>
<thead>
<tr>
<th>Study</th>
<th>Diagnostic Tool</th>
<th>Sample Size</th>
<th>Prevalence Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DC-LD</td>
<td>101</td>
<td>19%</td>
</tr>
<tr>
<td></td>
<td>ICD-10-DCR</td>
<td>101</td>
<td>0.1%</td>
</tr>
<tr>
<td></td>
<td>DSM-IV-TR</td>
<td>101</td>
<td>0.1%</td>
</tr>
<tr>
<td>Cooper &amp; Bailey (2001)</td>
<td>ICD-10-DCR</td>
<td>207</td>
<td>15%</td>
</tr>
<tr>
<td>Bhaumik et al (2008)</td>
<td>ICD-10</td>
<td>2,711</td>
<td>20%</td>
</tr>
</tbody>
</table>
2.5.2 Standardized Assessments

Three studies used standardized assessment tools designed to assess behavioural conditions in individuals with intellectual disabilities. One such study used the Aberrant Behavior Checklist (ABC: Aman & Singh, 1986) to assess challenging behaviour in 318 participants from South and Mid Wales, as described earlier (Matthews et al., 2008). The ABC has five subscales and a score above 45 is used to identify challenging behaviours. Overall, 15% of the sample was found to have challenging behaviours.

The remaining two studies found much higher prevalence estimates of behaviour disorders, which were over 40%. The highest prevalence estimate was found by Deb, Thomas and Bright (2001b). One hundred and one individuals from South Wales were assessed for behaviour disorders using the Disability Assessment Schedule (DAS: Holmes et al., 1982). Behaviours were rated as present if they were severe or occurred frequently, more than three times during the week. Overall, 60% of the individuals had a behaviour disorder, while the prevalence of psychiatric and/or behavioural conditions was 64% in the cohort.

Another study using a similar approach to diagnose behaviour disorders was done by Smith et al. (1996). Individuals from the Leicestershire Learning Disabilities Information Co-ordination Centre database were identified to take part in the study investigating the prevalence of behavioural problems among those with intellectual disabilities. Information was collected using a modified Disability Assessment Schedule. In total, 2202 individuals, 18 years and over, participated in the study. The authors found that 64% of the individuals had one or more maladaptive behaviours, while 39% had behaviours that were severe or frequent, manifesting more than three times a week.
The prevalence estimates of behavioural conditions assessed by standardized tools are summarized in Table 6. As can be seen, the prevalence estimates most commonly reported are 60% and 64%. The prevalence of behavioural conditions based on the ABC is much lower. However, the discrepancy in the estimates is likely related to the diagnostic tool used. The prevalence of behavioural disorders will be further explored through surveys of service recipients.

Table 6. Results for Behavioural Conditions by Standardized Assessment Tool

<table>
<thead>
<tr>
<th>Study</th>
<th>Diagnostic Tool</th>
<th>Sample Size</th>
<th>Prevalence Estimates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Matthews et al (2008)</td>
<td>ABC</td>
<td>318</td>
<td>15%</td>
</tr>
<tr>
<td>Deb, Thomas &amp; Bright (2001a)</td>
<td>DAS</td>
<td>101</td>
<td>60%</td>
</tr>
<tr>
<td>Smith et al (1996)</td>
<td>Modified DAS</td>
<td>2,202</td>
<td>64% if any maladaptive behaviour; 39% if limited to severe or frequent behaviours</td>
</tr>
</tbody>
</table>

2.5.3 Surveys of Service Recipients

The prevalence of behaviour conditions is also assessed through surveys of service recipients and their caretakers. A study done by Lund (1985) found a low prevalence of behaviour disorders among those with intellectual disabilities. Aside from investigating psychopathology, the author also used the Medical Research Council - Schedule of Handicaps, Behaviour, and Skills (MRC-HBS) to assess the prevalence of behaviour disorders in the sample. It was found that 11% of the individuals had a behaviour disorder, defined as “behaviour causing problems in contact with other people, or demanding special care” (Lund, 1985).

This is in contrast to the other studies relying on surveys, which found much higher prevalence of behavioural conditions among individuals with intellectual disabilities. Lowe et al (2007) approached all services providing support for individuals with learning disabilities in South Wales, UK, and invited 928 clients, 19 years and over,
to be part of the study. Overall, 705 individuals completed the study, which assessed behaviour problems using the Individual Schedule filled out by the primary caregiver (Alborz et al., 1994). Of the participants, 58% showed at least one serious behaviour or a behaviour that needed to be controlled. Similarly, the survey of individuals with intellectual disabilities in six American states mentioned earlier also investigated behavioural conditions among the population (Lakin et al., 2007). In total, 53% of the individuals had a challenging behaviour according to the National Core Indicators Survey.

A somewhat lower prevalence estimate was obtained using the Inventory for Client and Agency Planning (ICAP: Bruininks et al., 1986). The ICAP was used to assess problem behaviours among 629 participants from a sample of 1192 individuals with intellectual disabilities in Massachusetts (Freedman & Chassler, 2004). Problem behaviours were grouped into three subcategories (self-injury, disruptive behaviour, and uncooperative behaviour) and the authors found that 46% of the sample exhibited at least one problem behaviour.

Another study found a similar prevalence of problem behaviours. In total, 1825 individuals captured in the Birmingham Special Needs Register were assessed (Clarke et al., 1990). The study investigated all individuals with intellectual disabilities over 20 years of age who resided in hospitals, community residential facilities, or with family members. Behaviour disorders were defined as “behaviours that caused the individual or their caregiver a severe problem (either occasionally or frequently)”, and affected 41% of the participants (Clarke et al., 1990).
The most commonly reported prevalence estimates of behavioural conditions in surveys are between 41% and 58% (Table 7). However, there is an outlier. The study by Lund (1985) found a prevalence of behavioural conditions of 11%. This could be due to numerous factors, such as the diagnostic tool, the individuals that were assessed, or the date of assessment, as all of the other studies were published in 1990 or later.

Table 7. Results for Behavioural Conditions by Survey of Service Recipients

<table>
<thead>
<tr>
<th>Study</th>
<th>Diagnostic Tool</th>
<th>Sample Size</th>
<th>Prevalence Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lund (1985)</td>
<td>MRC-HBS</td>
<td>302</td>
<td>11%</td>
</tr>
<tr>
<td>Lowe et al (2007)</td>
<td>Individual Schedule</td>
<td>705</td>
<td>58%</td>
</tr>
<tr>
<td>Lakin et al (2007)</td>
<td>NCI Consumer Survey</td>
<td>2,720</td>
<td>53%</td>
</tr>
<tr>
<td>Freedman &amp; Chassler (2004)</td>
<td>ICAP</td>
<td>629</td>
<td>46%</td>
</tr>
<tr>
<td>Clarke et al (1990)</td>
<td>Behaviour disorder definition</td>
<td>1,825</td>
<td>41%</td>
</tr>
</tbody>
</table>

2.6 Dual Diagnosis and Severity of Intellectual Disability

Numerous studies have shown higher prevalence estimates of psychopathology among individuals with greater intellectual disability. Individuals with severe or profound intellectual disabilities were more likely to have mental ill-health of any type compared to individuals with mild or moderate intellectual disability (Cooper et al, 2007). In a study done by Cooper and Bailey (2001), it was found that those individuals with psychiatric disorders tended to have more severe intellectual disability. Lund (1985) also found that there seemed to be an increase in the prevalence of psychiatric conditions among those individuals who had a more severe level of intellectual disability.

The characteristics of participants, mainly the level of intellectual disabilities, also seem to be related to varying prevalence estimates of behaviour disorders. Several authors reported similar results for the prevalence of behaviour disorders. In a study by Cooper and Bailey (2001), behaviour disorders were more common among those with severe intellectual disability. Higher prevalence estimates of behaviour disorders were
also found to be significantly associated with more severe levels of intellectual disability in another study (Deb, Thomas & Bright, 2001b). However, Iverson and Fox (1989) found the reverse. Of the study participants, 54.5% of the individuals with mild intellectual disability, 31.5% of those with moderate intellectual disability, and 25.9% of those with severe or profound intellectual disability had psychopathology. The authors indicated two reasons that could account for this. Firstly, individuals with mild intellectual disability were thought to be underrepresented in the sample as not all individuals with this level of disability receive services, but only those with most difficulties. Secondly, the PIMRA is based on the DSM-III which asks about voiced symptoms (Iverson & Fox, 1989). Challenges exist in diagnosing psychiatric disorders in those with severe and profound intellectual disabilities due to their limitations or inability to communicate symptoms, therefore the clinicians must rely on presenting behaviours (Holden & Gitlesen, 2004).

2.7 Summary of Findings

Based on the results provided in this chapter, the prevalence of psychiatric conditions ranged from just over 14% to 64%. However, the majority of the studies presented prevalence estimates between 30% and 45%. The prevalence of behaviour disorders ranged from over 10% to almost 64% in the chosen articles. In one study, two diagnostic criteria found the prevalence of behaviour disorders to be 0.1%, although different diagnostic criteria found much higher prevalence estimates in the same study. Overall, most studies indicated the prevalence of behaviour disorders to be greater than 40% for standardized assessments and surveys of service providers. This was in sharp
contrast to the results found using the diagnostic manuals to assess behavioural conditions. The prevalence estimates were around 15% to 23%.

In conclusion, the discrepancy in the prevalence estimates for both psychiatric and behavioural conditions may be due to various factors. The main reasons are likely to be related to: 1) the assessment tools and definitions used to diagnose and describe psychiatric conditions; and 2) the characteristics of participants. The review of literature also found conflicting results regarding the relationship between increased severity of intellectual disability and prevalence of dual diagnosis.

2.8 Implications

Research has shown that individuals with intellectual disabilities have a high prevalence of specific mental health problems which are not common among the general population, for example, pervasive developmental disorders and behavioural disorders (Cooper & Bailey, 2001). Knowledge about the prevalence of psychiatric and behavioural conditions among those individuals with intellectual disabilities is crucial for service and treatment planning purposes, as well as for resource allocation to ensure that individuals with intellectual disabilities and their caregivers receive the appropriate supports (Kerker et al, 2004).

The broad ranges in the prevalence of psychiatric and behaviour disorders indicate the need for further research in this area. Future population-based studies should use standardized assessment methods to allow for the comparison of results among various study sites using clear sample descriptions and stratified analyses to enhance comparability across studies.
As seen in the literature review, the prevalence of dual diagnosis greatly differs. None of the reported studies investigated the prevalence of psychiatric or behavioural conditions among the Canadian population. In order to plan services for the dual diagnosis population in Canada, it would be ideal to know the prevalence estimates in a Canadian context. This lack of information in Canada led to the development of this Master of Science thesis.

2.9 Thesis Goals

The intent of this thesis was to use existing data to derive an estimate of the proportion of adults in Canada with an intellectual disability who also have psychiatric and/or behavioural conditions, and to describe the extent to which these individuals access health services for their conditions.
CHAPTER 3: STUDY DESIGN AND METHODS

3.1 Study Design

This study was a secondary analysis of two cross-sectional, population-based surveys [the Canadian Community Health Survey (Statistics Canada, 2005) and the Participation and Activity Limitation Survey (Statistics Canada, 2006)] and a secondary analysis of data from the Survey of Adults with Intellectual Disabilities in South Eastern Ontario 2008/09 (SAID-SEO: Ouellette-Kuntz et al, 2007b). Appropriate questions from each of the three data sources were used and are listed in Appendix E.

3.2 The Canadian Community Health Survey

3.2.1 Data Source

The Canadian Community Health Survey (CCHS), Cycle 3.1 (2005), is a cross-sectional survey of 130,000 Canadians aged 12 years and over, representing residents of all provinces and territories. A multistage stratified cluster sampling design was used in the survey (Health Reports, 2002). Individuals who live on Indian Reserves, Canadian Forces Bases, and remote areas are not included in the sample (Statistics Canada, 2005). Proxy responses are allowed for some survey questions, however, proxy respondents were not allowed for the variables assessed in the thesis. Technical details about the CCHS may be found in documentation by Statistics Canada, Catalogue 82-003-XIE (Health Reports, 2002).

3.2.2 Data Measures

The following section describes the variables that were selected from the CCHS for the purpose of the study (Statistics Canada, 2005a).
3.2.2.1 Measurement of Dual Diagnosis

To estimate the proportion of adults with intellectual disabilities, a question was used to identify individuals with a developmental disability. Examples of developmental disabilities were autism, Down's syndrome, Asperger's syndrome, and Rett syndrome. To classify an individual as having a dual diagnosis, this question was cross-tabulated with questions in the survey that assessed mental illness. Mental illness was defined as having one or more of the following conditions: schizophrenia; mood disorders – depression, bipolar disorder, mania, or dysthymia; anxiety disorders – phobia, obsessive-compulsive disorder, or panic disorder; and eating disorders – anorexia or bulimia. The wording of the questions may be found in Appendix E.

3.2.2.2 Measurement of Reported Use of Health Services

To determine mental health care utilization among persons with a dual diagnosis, the questions used to identify the dual diagnosis population were cross-tabulated with health care utilization questions. Four questions were chosen that asked if the individual had contact (seen or talked on the phone) in the past 12 months with (1) a family doctor or general practitioner, (2) a medical specialist, (3) a social worker or counsellor, or (4) a psychologist, about their physical, emotional or mental health. Due to data suppression, questions regarding contacts with a family doctor or general practitioner, or a medical specialist, were not included in the analysis. The questions regarding contact with a social worker or counsellor, or a psychologist were combined.

3.2.2.3 Measurement of Demographic Variables

Data regarding the sex, age, and province of residence of the respondents were included in the analysis. Only individuals 18 years of age or older were included in the
analysis. The age variable was recoded into seven age groups: 18-19, 20-24, 25-34, 35-44, 45-54, 55-64, 65+ years old. Where data needed to be suppressed, the two oldest age groups were combined. When the age data were cross-tabulated with data regarding contacts with mental health care professionals, two age groups were created due to data suppression (<25, 25+ years old). Data regarding province of residence were grouped to create five geographical areas: British Columbia and Alberta, Saskatchewan and Manitoba, Ontario, Québec, and Maritime Provinces (New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador). Canadian Territories (Yukon, Northwest Territories, and Nunavut) were excluded due to low cell counts.

3.2.3 Data Management

In order to access the Canadian Community Health Survey, a request was made to Statistics Canada and permission was obtained to use the Master File in the Queen’s University Research Data Centre. The survey data were recoded as mentioned above. Responses where the answer was ‘refusal’, ‘don’t know’, or ‘not stated’ were not included in the analysis. SPSS software version 6.0 for SunRay Microsystems was used to analyze the national surveys. Data with cell counts less than 5 were suppressed and the estimates were not released due to confidentiality. Appropriate population weights were applied to the national survey data. In order to calculate the 95% confidence intervals for the prevalence estimates, bootstrap weights and Statistics Canada’s BOOTVAR macros were used for SPSS software version 14.0 (Statistics Canada, 2004).

Using the bootstrap method, the standard error was calculated for each estimate reported. From this, the coefficient of variation was obtained by dividing the standard error by the estimate. The quality of the estimate is quantified by Statistics Canada based
on the size of the coefficient of variation, as a small value corresponds to smaller variability in the sample population (Statistics Canada, 2006a; Statistics Canada, 2006c). This is related to the width of the confidence intervals, which are reported in this study. When the confidence intervals are narrow, there is less variability in the sample and the estimate is more reliable. In the context of this thesis, the term ‘data quality’ will be used to describe the precision of the estimates obtained from the national surveys, as measured by the coefficient of variation.

For the CCHS and PALS data, the following coefficient of variation cut-offs are suggested by Statistics Canada and were used when reporting the data:

(a) If the coefficient of variation is 16.5% or less, the estimate can be considered for release without any special notation.

(b) If the coefficient of variation is greater than 16.5% but less than or equal to 33.3%, the estimate can be considered for release but will be identified with the letter ‘E’ in superscript to caution about the high sampling variability.

(c) If the coefficient of variation is greater than 33.3%, it is recommended by Statistics Canada to not release the estimate due to the quality. However, the data can be released and will be identified with the letter ‘F’ in superscript and the following warning: “The user is advised that the data do not meet Statistics Canada’s quality standards for this statistical program. Conclusions based on these data will be unreliable and most likely invalid. These data and any consequent findings should not be published. If the user chooses to publish these data or findings, then this disclaimer must be published with the data.” (Statistics Canada, 2006a; Statistics Canada, 2006c).
3.2.4 Data Analysis

Among the whole population, the proportion of individuals who have an intellectual disability was calculated. The data were further analyzed to calculate age- and sex-specific proportions of intellectual disability among the Canadian population. Proportions were also calculated for each geographical region. A similar analysis was then done among individuals with an intellectual disability to provide a profile of individuals with a dual diagnosis. The proportion of individuals with an intellectual disability who also had a psychiatric or behavioural condition was calculated. Once again, sex- and age-specific proportions were calculated. The proportion of individuals with an intellectual disability and a dual diagnosis was calculated for each geographical area. Lastly, the proportion of individuals with a dual diagnosis who had contact with a mental health professional during the past 12 months was calculated, and an age-specific sub-analysis was undertaken. Similar statistics were prepared for individuals who did not have an intellectual disability but had a psychiatric or behavioural condition. For each above-mentioned sub-analysis, 95% confidence intervals were compared to determine statistical significance.

3.3 The Participation and Activity Limitation Survey

3.3.1 Data Source

The second survey used was the Participation and Activity Limitation Survey (PALS: 2006). The survey had a two-phase stratified sample design based on data collected in the 2006 Census (Statistics Canada, 2006a). The sample population for the PALS was selected from the Census sampling frame and included individuals who noted having activity limitations on the Census. The PALS is a cross-sectional survey of 47,500
individuals including 39,000 adults aged 15 years and over. Individuals living on Indian Reserves, Canadian Forces Bases, and institutions are excluded from the sampling frame (Statistics Canada, 2006). Technical details about the PALS may be found in documentation by Statistics Canada, Catalogue no. 89-628-XIE No. 001 (Statistics Canada, 2006a). A separate dataset containing demographic information about individuals who completed the Census but did not indicate activity limitations was accessed. This dataset was combined with the PALS dataset.

Proxy respondents (someone who answers the survey on behalf of the selected individual) were selected when a respondent was not present during the duration of the survey, the respondent did not speak English or French, or the respondent could not participate in the survey due to a physical or mental condition. The most common reason for proxy respondents (in 60% of the cases) was due to a health, physical, or mental condition. The chosen proxy respondent was required to be knowledgeable about the individual’s activity and participation limitations, as well as the difficulties and challenges the person faced as a result of these limitations (Statistics Canada, 2006b).

3.3.2 Data Measures

The following section describes the variables that were selected from the PALS for the purpose of the study (Statistics Canada, 2006b).

3.3.2.1 Measurement of Dual Diagnosis

To estimate the proportion of adults with intellectual disabilities, a question was used to identify individuals with a developmental disability. Developmental disabilities or disorders included as examples, Down syndrome, autism, Asperger syndrome, and mental impairment due to a lack of oxygen at birth. To classify an individual as having a
dual diagnosis, this question was cross-tabulated with a question that assessed emotional, psychological, or psychiatric conditions that the individual reported had lasted or were expected to last for 6 months or more. These conditions included among others, phobias, depression, schizophrenia, and drinking or drug problems. The wording of the questions may be found in Appendix E.

3.3.2.2 Measurement of Reported Use of Health Services

To determine mental health care utilization among persons with a dual diagnosis, the questions used to identify the dual diagnosis population were cross-tabulated with a question about health care utilization. The chosen question asked if in the past 12 months, the individuals had seen or talked to a physician regarding their physical, emotional or mental condition.

3.3.2.3 Measurement of Demographic Variables

Data regarding the sex, age, and province of residence of the respondents were included in the analysis. Only individuals 18 years of age or older were included in the analysis. The age variable was recoded into seven age groups: 18-19, 20-24, 25-34, 35-44, 45-54, 55-64, 65+ years old. Where data needed to be suppressed, the two oldest age groups were combined. When the age data were cross-tabulated with data regarding contacts with mental health care professionals, two age groups were created due to data suppression (<25, 25+ years old). Data regarding province of residence were grouped to create five geographical areas: British Columbia and Alberta, Saskatchewan and Manitoba, Ontario, Québec, and Maritime Provinces (New Brunswick, Nova Scotia,
Prince Edward Island, Newfoundland and Labrador). Canadian Territories (Yukon, Northwest Territories, and Nunavut) were excluded due to low cell counts.

### 3.3.3 Data Management

In order to access the Participation and Activity Limitation Survey, a combined request with the CCHS was made to Statistics Canada and permission was obtained to use the Master File in the Queen’s University Research Data Centre. The survey data were recoded as mentioned above. Responses where the answer was ‘refusal’, ‘don’t know’, or ‘not stated’ were not included in the analysis. SPSS software version 6.0 for SunRay Microsystems was used to analyze the national surveys. Data with cell counts less than 10 were suppressed and the estimates were not released due to confidentiality. Appropriate population weights were applied to the national survey data. In order to calculate the 95% confidence intervals for the prevalence estimates, bootstrap weights were used for Stata version 10.0 software. When assessing data quality, the same coefficient of variation cut-offs were used as described for the CCHS in Section 3.2.3 – Data Management.

### 3.3.4 Data Analysis

Among the whole population, the proportion of individuals who have an intellectual disability was calculated. The data were further analyzed to calculate age- and sex-specific proportions of intellectual disability among the Canadian population. Proportions were also calculated for each geographical region. A similar analysis was then done among individuals with an intellectual disability to provide a profile of individuals with a dual diagnosis. The proportion of individuals with an intellectual disability who also had a psychiatric or behavioural condition was calculated. Once
again, sex- and age- specific proportions were calculated. Proportion of dual diagnosis was calculated for each geographical area. Lastly, the proportion of individuals with a dual diagnosis who had contact with a mental health professional during the past 12 months was calculated, and an age-specific sub-analysis was undertaken. Similar statistics were prepared for individuals who did not have an intellectual disability but had a psychiatric or behavioural condition. For each above-mentioned sub-analysis, 95% confidence intervals were compared to determine statistical significance.

3.4 The Survey of Adults with Intellectual Disabilities in South Eastern Ontario

3.4.1 Data Source

The SAID-SEO is a cross-sectional study that collected detailed clinical information for a sample of 192 adults with an intellectual disability living in South Eastern Ontario (Ouellette-Kuntz et al., 2007b). A stratified random sample of individuals was selected from the 2006 update of the Geographic Registry in Intellectual Disability (GRID: Ouellette-Kuntz et al., 2007b). The GRID collects information from 36 developmental service sector agencies across six counties of the South Eastern Ontario region (Ouellette-Kuntz et al., 2007a). A total of 20 agencies agreed to participate in the SAID-SEO and 387 clients were approached. Data were collected for 192 clients who agreed to participate in the study.

Information regarding these individuals was obtained through a telephone interview with a proxy respondent, such as a family member or caretaker. The participants were recruited and data were collected in 2008 and 2009. The presented results consist of a part of the study, which also included the assessment of psychiatric and behavioural conditions through standardized tools such as the Scales of Independent
Behavior-Revised (SIB-R) Short Form, the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) Checklist, the Anxiety Depression and Mood Screen (ADAMS), and the Reiss Screen for Maladaptive Behavior (RSMB).

3.4.2 Data Measures

The following section describes the variables that were selected from the SAID-SEO for the purpose of the study.

3.4.2.1 Measurement of Dual Diagnosis

For the SAID-SEO, the individuals were selected from the GRID (2006), which collects information regarding clients with a developmental disability who are served by developmental service agencies across the region. According to the Developmental Services Act (1990), a developmental disability is “a condition of mental impairment, present or occurring during a person’s formative years, that is associated with limitations in adaptive behaviour”. As this definition conveys eligibility for supports from developmental service agencies, it is assumed that all individuals included in the survey had such a disability.

To assess dual diagnosis, the proxy respondent was asked if the individual currently had a diagnosed psychiatric or behavioural condition. The presence of dual diagnosis could also be measured using the results of standardized assessment tools of psychopathology, such as the PAS-ADD, ADAMS, and RSMB, which were used in the study. However, proxy report of psychiatric or behavioural conditions was chosen in order to correspond to the methods used in the national surveys.
3.4.2.2 Measurement of Reported Use of Mental Health Services

To determine the use of mental health services, the proxy respondent was asked if the person with a dual diagnosis was currently receiving any services to help with their psychiatric or behavioural conditions.

3.4.2.3 Measurement of Demographic Variables

Data regarding the sex and age of the adult with an intellectual disability were included in the analysis. Only individuals 18 years of age or older were selected for the study. The birth dates were recoded into seven age groups: 18-19, 20-24, 25-34, 35-44, 45-54, 55-64, 65+ years old. When the age data were cross-tabulated with data regarding contacts with mental health care professionals, two age groups similar to those in the CCHS and PALS were created (<25, 25+ years old).

3.4.3 Data Management

In order to access the SAID-SEO data, permission was obtained from the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities. The survey data were recoded as mentioned above. Cell counts less than 5 were suppressed and the estimates were not released due to confidentiality. SPSS software version 17.0 was used to analyze the survey. 95% confidence intervals were calculated for the prevalence estimates.

3.4.4 Data Analysis

Among the whole sample, the proportion of individuals with an intellectual disability who also had a psychiatric or behavioural condition was calculated. Sex- and age- specific proportions were calculated. The proportion of individuals with a dual
diagnosis who had contact with a mental health professional was calculated, and an age-specific sub-analysis was undertaken. For each above-mentioned sub-analysis, 95% confidence intervals were compared to determine statistical significance.

3.5 Combined Analysis

The results from each of the three surveys were analyzed for comparable questions. The proportions and their 95% confidence intervals were compared between surveys. For subgroup analyses, any evident trends in the results were described.

3.6 Ethical Considerations

Permission was obtained from the Queen’s University Research Ethics Board to do a secondary analysis of national survey data (CCHS and PALS) and the SAID-SEO data. A copy of the certificate is found in Appendix F.
CHAPTER 4: RESULTS

In the following section, the results from the CCHS, PALS, and SAID-SEO are presented. As described in Chapter 3: Study Design and Methods, estimates noted with an ‘E’ are of poor or marginal quality (coefficient of variation >16.5% and ≤33.3%) and should be interpreted with caution. They are also presented in a dark grey colour. Those estimates that are identified with an ‘F’ are of unacceptable quality (coefficient of variation >33.3%) due to high sampling variability. These estimates are presented in a light grey colour.

4.1 Prevalence of Intellectual Disabilities in Canada

The prevalence of intellectual disabilities among adults in Canada was investigated using data from the CCHS and PALS surveys. According to the CCHS, Cycle 3.1 (2005), 51,655 or 0.2% of the Canadian adult population has an intellectual disability. The prevalence of individuals with an intellectual disability is slightly higher in the PALS (2006), where it is 0.5% representing 112,919 individuals.

4.1.1 Prevalence of Intellectual Disabilities in Canada by Sex

The prevalence of intellectual disability by sex is provided in Table 8. In the CCHS, the prevalence of intellectual disability was 0.2% for both males and females. These proportions are significantly higher in the PALS, where 0.6% of the males and 0.4% of the females have an intellectual disability. However, the difference in prevalence estimates between males and females is not statistically significant.
Table 8. Proportion of Canadian population with an intellectual disability by sex, CCHS (2005) and PALS (2006)

<table>
<thead>
<tr>
<th></th>
<th>CCHS (2005)*</th>
<th></th>
<th>PALS (2006)*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>% (95% CI)</td>
<td>Number</td>
</tr>
<tr>
<td>Male</td>
<td>28,484</td>
<td>0.2 (0.18-0.30)</td>
<td>63,582</td>
</tr>
<tr>
<td>Female</td>
<td>23,171</td>
<td>0.2 (0.12-0.25)</td>
<td>49,337</td>
</tr>
<tr>
<td>Total</td>
<td>51,655</td>
<td>0.2 (0.17-0.26)</td>
<td>112,919</td>
</tr>
</tbody>
</table>

*The estimates are adjusted using bootstrap weights.
#The estimate is considered to be of poor quality due to high sampling variability.

4.1.2 Prevalence of Intellectual Disabilities in Canada by Age

Table 9 and Figure 3 show the proportion of the Canadian adult population with an intellectual disability by age groups. Once again, the proportion of individuals with an intellectual disability is statistically significantly higher in the PALS as compared to the CCHS for most age groups. Almost 60% of the population with intellectual disabilities is under the age of 35 in the CCHS. The population distribution is slightly different in the PALS where over 35% of those with an intellectual disability are under 35 years of age.

In the CCHS, a greater proportion of individuals in the 20 to 24 age group have an intellectual disability compared to the other age groups. In contrast, the proportion of intellectual disabilities is lower among individuals who are 55 years of age or older compared to the other age groups. A similar pattern is evident in the PALS. A significantly lower proportion of individuals in the oldest age group (65+ years old) have an intellectual disability when compared to the other age groups in the survey. In contrast, individuals in the youngest age groups (18 to 24 years old) have a higher prevalence of intellectual disability than the older age groups in the national survey.
Table 9. Proportion of Canadian population with an intellectual disability by age group, CCHS (2005) and PALS (2006)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>CCHS (2005)*</th>
<th>PALS (2006)*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>% (95% CI)</td>
</tr>
<tr>
<td>18-19</td>
<td>2,962</td>
<td>0.4(^{\text{E}}) (0.11-0.63)</td>
</tr>
<tr>
<td>20-24</td>
<td>12,351</td>
<td>0.6(^{\text{E}}) (0.32-0.79)</td>
</tr>
<tr>
<td>25-34</td>
<td>14,606</td>
<td>0.4(^{\text{E}}) (0.20-0.50)</td>
</tr>
<tr>
<td>35-44</td>
<td>8,404</td>
<td>0.2(^{\text{E}}) (0.10-0.23)</td>
</tr>
<tr>
<td>45-54</td>
<td>8,751</td>
<td>0.2(^{\text{E}}) (0.09-0.28)</td>
</tr>
<tr>
<td>55-64</td>
<td>1,436</td>
<td>&lt;0.1(^{\text{E}}) (0.01-0.07)</td>
</tr>
<tr>
<td>65+</td>
<td>3,145</td>
<td>&lt;0.1(^{\text{E}}) (0.03-0.13)</td>
</tr>
<tr>
<td>Total</td>
<td>51,655</td>
<td>0.2 (0.17-0.26)</td>
</tr>
</tbody>
</table>

*The estimates are adjusted using bootstrap weights.
\(^{\text{E}}\)The estimate is considered to be of poor quality due to high sampling variability.
\(^{\text{F}}\)The user is advised that the data do not meet Statistics Canada’s quality standards for this statistical program. Conclusions based on these data will be unreliable and most likely invalid. These data and any consequent findings should not be published. If the user chooses to publish these data or findings, then this disclaimer must be published with the data.

Figure 3. Proportion of Canadian population with an intellectual disability by age group, CCHS (2005) and PALS (2006)

The estimate is considered to be of poor quality due to high sampling variability.
\(^{\text{F}}\)The user is advised that the data do not meet Statistics Canada’s quality standards for this statistical program. Conclusions based on these data will be unreliable and most likely invalid. These data and any consequent findings should not be published. If the user chooses to publish these data or findings, then this disclaimer must be published with the data.
4.1.3 Prevalence of Intellectual Disabilities in Canada by Geographical Area

The proportion of individuals with an intellectual disability across geographical area follows a similar pattern in both surveys, as shown in Table 3 and Figure 3. In the CCHS, the proportion of intellectual disability in the adult population ranges from 0.2% to 0.3%, although the differences between geographical areas are non-significant (Table 10 and Figure 4). However, the estimates in the CCHS are of poor or marginal quality due to high sampling variability and should be used with caution.

In the PALS, the highest proportion of individuals who have an intellectual disability were living in the Maritime Provinces (Newfoundland, Prince Edward Island, Nova Scotia, New Brunswick: 0.6%) and Saskatchewan and Manitoba (0.6%). However, those residing in Quebec showed a lower prevalence of intellectual disability when compared to the before-mentioned geographical areas and these differences were statistically significant.

Table 10. Proportion of population with an intellectual disability by geographical area, CCHS (2005) and PALS (2006)

<table>
<thead>
<tr>
<th>Geographical Area</th>
<th>CCHS (2005)*</th>
<th>PALS (2006)*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>% (95% CI)</td>
</tr>
<tr>
<td>Newfoundland, Prince Edward Island, Nova Scotia, New Brunswick</td>
<td>4,931</td>
<td>0.3* (0.15-0.39)</td>
</tr>
<tr>
<td>Quebec</td>
<td>9,623</td>
<td>0.2* (0.09-0.24)</td>
</tr>
<tr>
<td>Ontario</td>
<td>19,377</td>
<td>0.2* (0.13-0.28)</td>
</tr>
<tr>
<td>Saskatchewan, Manitoba</td>
<td>4,118</td>
<td>0.3* (0.13-0.41)</td>
</tr>
<tr>
<td>British Columbia, Alberta</td>
<td>13,607</td>
<td>0.2* (0.15-0.33)</td>
</tr>
<tr>
<td>Total</td>
<td>51,655</td>
<td>0.2 (0.17-0.26)</td>
</tr>
</tbody>
</table>

*The estimates are adjusted using bootstrap weights.
*The estimate is considered to be of poor quality due to high sampling variability.
4.2 Dual Diagnosis in Canada and South Eastern Ontario

In this section, the proportion of adults with an intellectual disability who also have a psychiatric or behavioural condition (dual diagnosis) will be presented for all three surveys analyzed – CCHS, PALS, and SAID-SEO. The CCHS estimates the proportion of adults with an intellectual disability who have a dual diagnosis to be 31%. This proportion was slightly higher in the PALS at 44% although the difference is not statistically significant. Similarly, the prevalence found in South Eastern Ontario through the SAID-SEO was 33% and was not statistically significantly lower than that found in the PALS. The CCHS and SAID-SEO prevalence estimates did not differ statistically.

4.2.1 Dual Diagnosis in Canada and South Eastern Ontario by Sex

The proportion of dual diagnosis by sex is presented in Table 11. For all three surveys, a difference between prevalence estimates among males and females was not
detected. However, the confidence intervals are very wide indicating poor precision.

Similarly, a difference between males and females was not detected between the surveys.

Table 11. Proportion of adults with intellectual disabilities with a dual diagnosis by sex, CCHS (2005), PALS (2006), and SAID-SEO (2008/09)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>% (95% CI)</td>
<td>Number</td>
</tr>
<tr>
<td>Male</td>
<td>8,594</td>
<td>30.2(^E) (19.8-40.5)</td>
<td>29,826</td>
</tr>
<tr>
<td>Female</td>
<td>7,189</td>
<td>31.0(^E) (15.1-46.9)</td>
<td>20,227</td>
</tr>
<tr>
<td>Total</td>
<td>15,783</td>
<td>30.6 (21.1-40.0)</td>
<td>50,053</td>
</tr>
</tbody>
</table>

*The estimates are adjusted using bootstrap weights.  
\(^E\) The estimate is considered to be of poor quality due to high sampling variability.

4.2.2 Dual Diagnosis in Canada and South Eastern Ontario by Age

Table 12 and Figure 5 show the proportion of individuals with a dual diagnosis by age group. Most of the estimates for the CCHS are of unacceptable quality due to a high coefficient of variation and as a result, conclusions cannot be drawn from the results. In regards to the PALS, the proportion of individuals with a dual diagnosis was lower in the youngest age group (18-19 years old), although this was not statistically significant. In addition, the estimate was of marginal or poor quality. The remaining estimates did not differ significantly from each other. In regards to the SAID-SEO data, none of the age groups differed statistically from each other.
Table 12. Proportion of adults with intellectual disabilities with a dual diagnosis by age group, CCHS (2005), PALS (2006), and SAID-SEO (2008/09)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>CCHS (2005)*</th>
<th>PALS (2006)*</th>
<th>SAID-SEO (2008/09)¹</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>% (95% CI)</td>
<td>Number</td>
</tr>
<tr>
<td>18-19</td>
<td>1,221</td>
<td>41.2F (4.3-78.2)</td>
<td>1,886</td>
</tr>
<tr>
<td>20-24</td>
<td>2,460</td>
<td>19.9F (4.2-35.6)</td>
<td>5,599</td>
</tr>
<tr>
<td>25-34</td>
<td>4,555</td>
<td>31.2E (10.3-52.1)</td>
<td>9,063</td>
</tr>
<tr>
<td>35-44</td>
<td>2,626</td>
<td>31.3E (14.8-47.7)</td>
<td>10,916</td>
</tr>
<tr>
<td>45-54</td>
<td>3,936</td>
<td>45.0E (18.1-71.9)</td>
<td>12,418</td>
</tr>
<tr>
<td>55+</td>
<td>986</td>
<td>21.5E (5.1-37.9)</td>
<td>10,171</td>
</tr>
<tr>
<td>Total</td>
<td>15,783</td>
<td>30.6 (21.1-40.0)</td>
<td>50,053</td>
</tr>
</tbody>
</table>

*The estimates are adjusted using bootstrap weights.
¹The first three age groups (18 to 34) were combined in the SAID-SEO data due to low cell counts.
F The estimate is considered to be of poor quality due to high sampling variability.
E The user is advised that the data do not meet Statistics Canada’s quality standards for this statistical program. Conclusions based on these data will be unreliable and most likely invalid. These data and any consequent findings should not be published. If the user chooses to publish these data or findings, then this disclaimer must be published with the data.

Figure 5. Proportion of adults with intellectual disabilities with a dual diagnosis by age group, CCHS (2005), PALS (2006), and SAID-SEO (2008/09)

---

LEGEND

- □ CCHS, 2005
- □ PALS, 2006
- □ SAID-SEO, 2008/09

1 The estimate is considered to be of poor quality due to high sampling variability.
1 The user is advised that the data do not meet Statistics Canada’s quality standards for this statistical program. Conclusions based on these data will be unreliable and most likely invalid. These data and any consequent findings should not be published. If the user chooses to publish these data or findings, then this disclaimer must be published with the data.
4.2.3 Dual Diagnosis in Canada by Geographical Area

The proportion of individuals with an intellectual disability and a co-morbid psychiatric or behavioural condition are presented in Table 13 and Figure 6 by geographical area. Once again, the estimates provided by the CCHS are of poor or unacceptable quality and cannot be commented on. In regards to the PALS data, the proportion of individuals with a dual diagnosis ranges from 37% to 49%. The results for the geographical areas are not statistically significantly different from each other.

Table 13. Proportion of adults with intellectual disabilities with a dual diagnosis by geographical area, CCHS (2005) and PALS (2006)

<table>
<thead>
<tr>
<th>Geographical Area</th>
<th>CCHS (2005)*</th>
<th></th>
<th>PALS (2006)*</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>% (95% CI)</td>
<td>Number</td>
<td>% (95% CI)</td>
</tr>
<tr>
<td>Newfoundland, Prince Edward Island, Nova Scotia, New Brunswick</td>
<td>1,970</td>
<td>40.0(^{E}) (17.8-62.1)</td>
<td>4,021</td>
<td>36.5 (29.5-43.5)</td>
</tr>
<tr>
<td>Quebec</td>
<td>2,717</td>
<td>28.2(^{E}) (7.6-48.9)</td>
<td>10,066</td>
<td>45.8 (31.1-60.6)</td>
</tr>
<tr>
<td>Ontario</td>
<td>4,266</td>
<td>22.0(^{E}) (8.2-35.9)</td>
<td>19,758</td>
<td>43.0 (29.3-56.8)</td>
</tr>
<tr>
<td>Saskatchewan, Manitoba</td>
<td>5,914</td>
<td>43.5(^{E}) (24.4-62.5)</td>
<td>3,884</td>
<td>42.9 (32.2-53.7)</td>
</tr>
<tr>
<td>British Columbia, Alberta</td>
<td>12,323</td>
<td></td>
<td>50,053</td>
<td>44.3 (37.5-51.1)</td>
</tr>
<tr>
<td>Total</td>
<td>15,783</td>
<td>30.6 (21.1-40.0)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*The estimates are adjusted using bootstrap weights.
\(^{E}\) The estimate is considered to be of poor quality due to high sampling variability.
\(^{E}\) The user is advised that the data do not meet Statistics Canada’s quality standards for this statistical program. Conclusions based on these data will be unreliable and most likely invalid. These data and any consequent findings should not be published. If the user chooses to publish these data or findings, then this disclaimer must be published with the data.
4.3 Reported Use of Health Services

Reported use of health services was analyzed for individuals with a dual diagnosis and is illustrated in Table 7 for all three surveys. Due to data suppression in the national surveys, only differences between two age groupings could be compared. As a result of the differences in the questions asked in the three surveys, caution should be exercised when comparing the estimates between the surveys.

Table 14. Reported use of health services by individuals with a dual diagnosis, CCHS (2005), PALS (2006), and SAID-SEO (2008/09)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>CCHS (2005)*1</th>
<th>PALS (2006)*2</th>
<th>SAID-SEO (2008/09)*3,4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>% (95% CI)</td>
<td>Number</td>
</tr>
<tr>
<td>&lt;25 years</td>
<td>1,556</td>
<td>42.3E (15.3-36.2)</td>
<td>25,272</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>87.9 (80.4-95.9)</td>
</tr>
<tr>
<td>≥25 years</td>
<td>5,974</td>
<td>49.4E (10.3-20.8)</td>
<td>579,408</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>95.5 (93.3-99.2)</td>
</tr>
<tr>
<td>Total</td>
<td>7,529</td>
<td>47.7E (31.3-64.1)</td>
<td>604,681</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>95.1 (92.2-97.9)</td>
</tr>
</tbody>
</table>

*The estimates are adjusted using bootstrap weights.
1 CCHS: reported going to a psychologist, social worker or counsellor; 2 PALS: reported seeing or talking to a physician, including a general physician or specialist; 3 SAID-SEO: proxy-reported use of mental health services
4 The data were not broken down by age due to low cell counts.
E The estimate is considered to be of poor quality due to high sampling variability.
F The user is advised that the data do not meet Statistics Canada’s quality standards for this statistical program. Conclusions based on these data will be unreliable and most likely invalid. These data and any consequent findings should not be published. If the user chooses to publish these data or findings, then this disclaimer must be published with the data.
For the CCHS, only visits to a psychologist, social worker or counsellor were reported due to data suppression of the estimates related to visits to a family doctor or general practitioner and visits to a medical specialist. In fact, the proportion of individuals who reported receiving health services from a family doctor, general practitioner, or medical specialist were very high and the reason for suppression was due to low cell counts of individuals who did not see these health professionals during the past year. Overall, 48% of those who are dually diagnosed reported going to a psychologist, social worker or counsellor in the past 12 months, although this estimate was of marginal or poor quality. When this was further investigated by age, the estimates were of poor or unacceptable quality and conclusions could not be drawn from the results. In comparison, the use of these health services among the general population with psychopathology was 6.5%.

In the PALS, over 95% of the individuals reported seeing or talking to a physician, including a general physician or specialist, about their physical, emotional or mental condition in the past year. Conversely, the general population affected by mental illness also reported frequent use of these services (95%). When the visits were broken down by age for the dually diagnosed individuals in the PALS, 88% of those under the age of 25 years and 96% of those 25 years of age or older had contact with a physician during the past year. The difference between the age groups was not statistically significant.

Lastly, data were collected about use of mental health services by individuals with a dual diagnosis in South Eastern Ontario. The analysis showed that 91% of the individuals had received some services for their psychiatric or behavioural condition. The

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results were not broken down by age due to the low number of individuals in the youngest age group. Overall, the majority of adults with a dual diagnosis have access to physicians as found in the PALS and SAID-SEO, and close to half of the sample in the CCHS was in contact with a psychologist, social worker or counsellor during the past year.
CHAPTER 5: DISCUSSION

In the following section, a summary of the findings from the analysis of three surveys (CCHS, PALS, SAID-SEO) will be presented. Next, the strengths and limitations of this thesis study will be discussed and the implications of the study will be offered. Following this, the conclusions of the study will be presented.

5.1 Main Findings

The proportion of adult Canadians with an intellectual disability is 0.2% according to the CCHS and 0.5% according to the PALS. More males than females have an intellectual disability, although the difference was not statistically significant. Intellectual disabilities are more prevalent in younger adults compared to older adults. The proportion of adults with a dual diagnosis was found to be 31% in the CCHS, 44% in the PALS, and 33% in the SAID-SEO. These prevalence estimates fall within the ranges reported in the literature. Lastly, the majority of the adults with a dual diagnosis report accessing health services. However, many of the presented estimates, especially those from the CCHS, were unreliable due to high coefficients of variation. Therefore, conclusions could not be drawn from the data due to the low quality of the estimates.

5.2 Strengths and Limitations of the Study

This thesis was the first known study to examine data from two national surveys – CCHS (2005) and PALS (2006) – to assess the prevalence of intellectual disabilities and dual diagnosis in Canada. The results highlight the gaps in knowledge regarding the prevalence of intellectual disabilities in Canada, the proportion of individuals with a dual diagnosis, and their health care use.
A major strength of the national survey data is that the resulting estimates are, in theory, generalizable to the Canadian population due to the application of sample weights to the data. However, selection bias and data quality must be taken into account when applying the results to the population with intellectual disabilities. Secondly, the variables used in the survey are available and accessible for analysis and differences across future surveys can be examined. As a result, this study can be easily reproduced. The SAID-SEO (2008/09) also had numerous strengths. The sample for the survey was chosen so that it would be representative of the population of individuals with intellectual disabilities residing in South Eastern Ontario. In addition, the survey allowed for responses from proxy respondents, ensuring that individuals with severe and profound intellectual disabilities could be included in the sample.

However, there are also limitations to using the survey data. Individuals with intellectual disabilities may be scarcely represented by the national surveys as the sampling frames exclude those who lived in institutions, such as long-term care facilities and hospitals (Statistics Canada, 2003). Statistics Canada estimates that the total population missed in the 2001 Census, which provided the survey frame for numerous surveys, was 3% (Standing Committee on Aboriginal Affairs and Northern Development, 2008).

In particular, individuals with severe or profound intellectual disability may be missed in the CCHS, as the survey is completed by the selected individual. Therefore, the individual may be higher functioning and have a milder form of intellectual disability. The exclusion of individuals with a severe intellectual disability may not be a problem for
the PALS though, which allows for proxy responses. The data are self-reported by the person or a proxy respondent, so the data collected may not be consistent.

Additionally, questions used to assess intellectual disability, dual diagnosis, and health care use, varied across the three surveys. As a result, differing populations could have been classified as having an intellectual disability, dual diagnosis, or being a health care service recipient, hence limiting comparability across the surveys. The level of intellectual disability, which is related to the prevalence of dual diagnosis, was not assessed in any of the surveys. Finally, the reliability and validity of the answers of individuals with intellectual disabilities and proxy respondents in the surveys are unknown.

Another limitation of using the national survey data is the inability to investigate numerous factors associated with intellectual disabilities, dual diagnosis, and health care use, due to low cell counts and data suppression. However, the major limitation of using national survey data is the quality of the estimate that is produced as measured by the coefficient of variation. Some of the reported estimates from the national surveys were of marginal, poor, or unacceptable quality due to high sampling variability, which would limit the generalizability of the results. This limited the conclusions that could have been made about the data, particularly in the CCHS. Due to data suppression, varied questions were used to investigate reported use of health services.

Lastly, the regional survey of individuals in South Eastern Ontario has a considerably smaller sample size and this may affect any comparisons being made between the surveys. The participation rate for the survey (around 50%) was good considering the significant challenges in assessing individuals with intellectual
disabilities, yet participation was incomplete (Ouellette & Bielska, 2009). The generalizability of the results outside of South Eastern Ontario is unknown.

5.2.1 Utility of National Health Surveys

In response to the lack of population-based Canadian studies, two national health surveys were examined to determine if they could act as a substitute indicator of dual diagnosis in Canada and potentially aid service and policy planners in learning more about this population with unique health care needs. It was found that although the prevalence of intellectual disabilities was lower than expected based on the literature, the surveys nonetheless arrived at a similar prevalence of dual diagnosis as found in the systematic review and from the SAID-SEO data.

However, a substantial amount of the estimates derived from the national surveys were of poor or unacceptable quality due to high sampling variability. This was especially the case for the CCHS data. Of the 32 estimates presented, 21 were of marginal or poor quality, while 8 estimates were of unacceptable quality and could not be assessed. In comparison, only 10 estimates from the PALS were of marginal or poor quality, while the remaining estimates did not have any issues with data quality.

Both the CCHS and PALS reported a lower prevalence of intellectual disabilities as compared to the literature, although the prevalence of intellectual disabilities in the PALS was higher, most probably due to the use of proxy respondents. However, both of the national surveys found that the estimates of the proportion of adults with a dual diagnosis were similar to those reported in the literature. Due to data quality, the PALS may be a better choice to examine the prevalence of dual diagnosis in Canada and how it varies among different subgroups when compared to the CCHS. In addition, the PALS is
the optimal option when investigating health care use among individuals with a dual diagnosis due to the quality of the estimates. The results of the present and future PALS cycles could potentially be used to investigate reported use of health care. However, the sampling frame used in the study may cause selection bias, as individuals with significant activity limitations are chosen to participate. Therefore, persons with a more severe level of intellectual disability or those with additional co-morbidities may be overrepresented.

Of the three surveys, the best approach for estimating the prevalence of intellectual disabilities, the proportion of these individuals with a dual diagnosis, and health care use among this population is through the PALS. Not only are the estimates of high quality (as shown by the coefficients of variation), the survey allows for proxy respondents therefore ensuring that individuals with severe intellectual disabilities are included in the survey. The data from the CCHS was mostly of poor quality, which limits the use of this survey. Finally, the applicability of the SAID-SEO data to other regions in Canada has not been determined, and as such the utility of this survey may be limited to South Eastern Ontario.

5.3 Interpretation of Findings

The following section presents the results of the analysis of the CCHS (2005), PALS (2006), and SAID-SEO (2008/09). They are broken down into the three major subgroups examined: individuals with intellectual disabilities, individuals with an intellectual disability and psychiatric or behavioural conditions (dual diagnosis), and individuals with a dual diagnosis who report using health care services.
5.3.1 Intellectual Disabilities

According to the CCHS, 0.2% of the population in Canada reports having an intellectual disability. In the PALS, this prevalence estimate is statistically significantly higher at 0.5%. The prevalence estimates are dissimilar due to differences in the sample populations participating in the surveys, and the manner in which information was collected for the surveys. Regarding the sample population, the PALS targets individuals who indicated having activity limitations on the Canadian Census as compared to the CCHS, which selected a random sample of households to survey. Therefore, individuals with intellectual disabilities were more likely to be selected to participate in the PALS if it was indicated on the Census that their disabilities affected their daily activities. These differences in selecting and surveying the samples for the CCHS and PALS will affect the estimates of intellectual disabilities when broken down further by sex, age, and geographical area.

Additionally, the PALS could have increased the likelihood of an individual with an intellectual disability being included in the survey as it allowed proxy respondents to complete the surveys on behalf of the selected individuals. The proxy respondents needed to be familiar with the challenges and difficulties the person faces due to the disability (Statistics Canada, 2006a). Overall, over 12% of the sample over the age of 15 years completed the PALS using a proxy respondent. The most common reason cited for proxy interviews for individuals who were 15 years or older was the inability to participate due to physical or mental conditions. This affected about 60% of the individuals who completed the survey through proxy respondents. Due to this, it is possible that individuals with intellectual disabilities were represented by proxy respondents and
thereby, the number of people with intellectual disabilities is higher in the PALS as compared to the CCHS. Conversely, the CCHS was completed by individuals with intellectual disabilities who can be assumed to be higher functioning, as proxy responses were not allowed for all questions. Therefore, individuals with more severe intellectual disabilities may not have been represented by the survey.

Nonetheless, both national surveys provide prevalence estimates of intellectual disability in adults that are lower than estimates in the literature especially considering the fact that the questions asked also include individuals with developmental disabilities, such as autism. An Australian government report reviewed the prevalence of intellectual disabilities in Australian and international literature and found it to be between 0.3% and 3.0% depending on the definitions used and the geographical locations investigated (Australian Institute of Health and Welfare, 2003). Another review of administrative databases found the prevalence estimate of intellectual disabilities to be between 1.2% and 1.3% in the United States of America and Australia, while being lower than 1% in England and Wales (Braddock et al, 2001). Lastly, a study done in South Eastern Ontario found the prevalence of administratively-defined intellectual disability (individuals identified by service providers) to be between 0.8% and 0.9% in Lanark County (Ouellette-Kuntz & Paquette, 2001).

The prevalence estimates presented by CCHS and PALS data may be lower than expected due to the population frame used in the studies. Both national surveys exclude individuals living in institutions and long-term care facilities. However, a proportion of individuals with intellectual disabilities reside in these settings. In 1999, an estimated 30,000 individuals in this population resided in institutions in Canada (Kaiser, 1999).
Therefore, it is probable that a portion of the population with intellectual disabilities is ineligible to participate in the national surveys, thereby lowering the estimate of the prevalence of intellectual disabilities in Canada derived from such surveys.

5.3.1.1 Intellectual Disabilities by Sex

In regards to the prevalence of intellectual disabilities by sex, the estimates for males and females were once again lower in the CCHS when compared to the PALS. This was likely due to the differences in sample selection and data collection between the surveys as addressed in Section 5.1.1. The prevalence of intellectual disability was higher among males, although the differences were not statistically different.

A study by Partington et al (2000) briefly reviewed the literature regarding the prevalence of intellectual disability among males and females. The authors found that males outnumbered females 3 to 2 in the diagnosis of intellectual disability in studies conducted over the last century. This is also the case in studies examining the prevalence of intellectual disabilities in children (Leonard et al, 2003). In a study in Western Australia, male children were 1.6 times more likely to be diagnosed with an intellectual disability compared to female children. The higher prevalence in males could be due to X-chromosome linked conditions resulting in mental retardation in the population with intellectual disabilities (Partington et al, 2000).

5.3.1.2 Intellectual Disabilities by Age

When intellectual disabilities were investigated by age, both surveys showed significantly lower estimates of intellectual disability among the oldest population, when compared to the other estimates in the survey. A somewhat similar result was found in an
Australian study, which reported that the prevalence of intellectual disabilities was higher among those who were 64 years of age or younger (1.3%) compared to those who were 65 years of age or older (0.2%) (Australian Institute of Health and Welfare, 2003). The lower life expectancy of individuals with intellectual disabilities compared to the general population has been documented (Bittles et al., 2002; Patja et al., 2000). Conversely, the youngest individuals in the PALS sample (18 to 24 year olds) had the highest prevalence of intellectual disability. This could possibly be due to more younger individuals being diagnosed for their condition as compared to the older groups of individuals.

5.3.1.3 Intellectual Disabilities by Geographical Area

Lastly, the prevalence of intellectual disabilities was analyzed by geographical area. The data presented in the CCHS was considered to be of poor quality, so the analysis focused on the results from the PALS. Overall, the Maritime Provinces, Saskatchewan and Manitoba had a significantly higher prevalence of intellectual disabilities as compared to the estimate of intellectual disability in Quebec. No literature was identified that assessed interprovincial differences in the prevalence of intellectual disabilities. However, it is likely that the majority of the sample in Quebec completed a French version of the PALS; the effect of translation on the estimates is unknown.

5.3.2 Dual Diagnosis

For all three surveys, the prevalence of psychiatric or behavioural conditions among those with intellectual disabilities fell within the range of estimates found in the literature reviewed in Chapter 2. The majority of the research studies found prevalence
estimates of dual diagnosis in the 30% to 40% range, although none of the studies were national health surveys.

In regards to studies which surveyed service recipients, the estimates reported by Lund (1985), Lowe et al (2007), and Lakin et al (2007), are between 28% and 31%. These estimates are similar to that found in the SAID-SEO, which was 33%. However, the estimates reported in the PALS were higher than those found among participants in the CCHS and SAID-SEO, although the differences were not statistically significant. It is possible that this is related to the sampling frame of the survey. Participants for the survey were selected from the population of individuals who reported activity limitations on the Canadian Census. Therefore, individuals with a dual diagnosis may be more likely to experience activity limitations in contrast to persons with an intellectual disability who are not dually diagnosed.

5.3.2.1 Dual Diagnosis by Sex

In all three surveys, the proportion of individuals with a dual diagnosis was slightly higher among males when compared to females, although the differences were not statistically significant. The finding that more males reported having a dual diagnosis as compared to females has been shown in previous research (Ouellette-Kuntz et al, 2007a; Lund, 1985). It has been reported in South Eastern Ontario that 60% of the individuals captured by the Geographic Registry in Intellectual Disabilities (GRID) database who have a dual diagnosis were male (Ouellette-Kuntz et al, 2007a). In a Danish study, Lund (1985) found a similar pattern, whereby the proportion of individuals with a dual diagnosis was 30% in the males and 26% in females, although the differences were not statistically significant.
The gender differences may also be caused by varied presentations of psychopathology between males and females. For example, severe challenging behaviour is especially common in males. In a study from the United Kingdom, 63% of the sample with challenging behaviours was male (Lowe et al, 2007). Such externalizing behaviour presents a significant burden on the caregivers (Maes et al, 2003). On the other hand, depressive symptoms are more common among females with an intellectual disability (Lunsky, 2003). Individuals with depressive symptoms may not seek medical help for their condition and their symptoms may not be as noticeable to caregivers. Therefore, it is possible that since males with intellectual disabilities commonly present with conditions that have externalized symptoms, they may be assessed for dual diagnosis at a higher rate than females who more commonly present with conditions that have internalized symptoms.

5.3.2.2 Dual Diagnosis by Age

The estimates for dual diagnosis, when broken down by age, were of poor quality for the CCHS and were not assessed. No significant differences were apparent in the PALS and SAID-SEO estimates.

However, some prevalence studies have shown differences in the age distribution of dual diagnosis. For example, the prevalence of dual diagnosis in the population with intellectual disabilities identified by the GRID database ranged from 35% to 44% among the different age groups (Ouellette-Kuntz et al, 2007a). Compared to those who were 18 to 19 years old, only the oldest age group (65-85 years) had a significantly lower estimate of dual diagnosis. Looking at psychiatric diagnoses among those with intellectual disabilities, a New York State study found the prevalence of dual diagnosis to be 24% in
those 21-44 years old, 32% in those 45-59 years old, 30% in those 60-74 years old, and 17% in those 75 years of age or older (Davidson et al., 2003). In an American study, the proportion of individuals with a dual diagnosis was greater among individuals who were 40 years old when compared to those who were 70 years old (Janicki et al., 2002).

Some authors investigated the relationship between age and specific psychiatric or behavioural conditions. In a Danish study, Lund (1985) found that dual diagnosis slightly increased with age, although this was mostly due to the higher prevalence of dementia in those who were 65 years of age or older. However, behaviour disorders were more common among younger individuals (Lund, 1985). This was also the case in another study, where the prevalence of severe challenging behaviour was higher among those who were between the age of 12 and 35 years old, compared to those who were older (Lowe et al., 2007).

5.3.3 Use of Health Services

Lastly, reported use of health services was investigated in the three surveys. For the CCHS, close to half of the respondents indicated contact with a psychologist, social worker or counsellor during the past year. This proportion was higher when compared to the use of these health services among the general population with psychopathology, which was 6.5%. Conversely, the general population affected by mental illness did not differ from individuals with a dual diagnosis in regards to contact with general health practitioners in the PALS. Both groups of individuals reported frequent use of these services (95%). Similarly, most individuals with a dual diagnosis in South Eastern Ontario also reported having contact with mental health services.
These high estimates of health service use are apparent in previous studies. In an American study, the authors found that all of the participants with intellectual disability, including those with a dual diagnosis, were in contact with a physician (Janicki et al., 2002). An analysis of the Welsh Health Survey of 1995, which surveyed a community-based sample of individuals with intellectual disabilities, indicated that 80% of the individuals were in contact with their general practitioner in the past year (Lennox & Kerr, 1997).

5.4 Implications of Findings

The number of individuals with intellectual disabilities affected by psychiatric or behavioural conditions must be known in order to plan service delivery and allocate resources to this population. In general, the results of the study supplement the available literature by providing three unique estimates of dual diagnosis, which are comparable to those already reported.

5.4.1 Implications for Practice

The results of the SAID-SEO study of individuals with intellectual disabilities have the most direct implications on the residents of South Eastern Ontario with and without a dual diagnosis. The results of the SAID-SEO, CCHS, and PALS will be shared with development service agencies in South Eastern Ontario. These may potentially be valuable for advocacy groups, as well as for service providers planning programs for individuals with intellectual disabilities.
5.4.2 Implications for Further Research

Through a review of the literature, it was found that there is a lack of Canadian, population-based studies examining the prevalence of dual diagnosis using standardized screening and assessment tools. Due to this, future research should consider incorporating standardized tools that have been developed specifically for individuals with intellectual disabilities, such as those presented in the literature review.

Regarding the quality of the estimates derived from the national surveys, particularly the CCHS, future research could focus on these studies becoming better suited for analyzing data about individuals with a dual diagnosis. In particular, the sample size of individuals who self-identify as having an intellectual disability would have to increase. One possible way to ensure that this happens without surveying individuals who live in institutions would be to allow for responses from proxy respondents who are familiar with the individual with an intellectual disability.

5.5 Conclusions

Psychiatric and behavioural conditions are present in about a third of the population with intellectual disabilities, as shown by the three surveys examined in this thesis. Among the surveys, the PALS presented the highest quality of data regarding the population with a dual diagnosis. Using the survey data, some variables were related to an increased prevalence of intellectual disabilities, such as residence in certain geographical areas of Canada. The surveys found that a majority of individuals with a dual diagnosis access some form of health services at least once a year. In order to examine these patterns further and to decide on service allocation, in-depth research at a local level needs to be undertaken, such as that in South Eastern Ontario.
REFERENCES


National Coalition on Dual Diagnosis (2008). *Dual Diagnosis: The most common and devastating disorder you’ve never heard of*. Centre for Addiction and Mental Health, Toronto, ON.


APPENDIX A:

Systematic Review Search Strategy
Database specific terminology and search dates.

<table>
<thead>
<tr>
<th>Database (Dates Searched)*</th>
<th>Database-specific Terminology</th>
</tr>
</thead>
<tbody>
<tr>
<td>OVID Medline (1980-2008)</td>
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<tr>
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<td>3) Developmental Disabilities/</td>
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<td>4) handicap.mp</td>
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<td>5) disability.mp</td>
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<td>7) mental disorder.mp. or Mental Disorders/</td>
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<td>8) psychiatr*.mp</td>
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<td></td>
<td>9) behavio*.mp</td>
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<td>10) 8 or 7 or 9</td>
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<td></td>
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<td>12) dual diagnosis.mp. or &quot;Diagnosis, Dual (Psychiatry)&quot;/</td>
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<td>13) dual disorder.mp</td>
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<td>17) occurrence.mp</td>
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<td></td>
<td>18) rate.mp</td>
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<td>19) 18 or 16 or 17</td>
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<td>21) 21  limit 20 to yr=&quot;1980 - 2009&quot;</td>
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<td>3) Developmental Disabilities/</td>
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<td>4) handicap.mp</td>
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<td></td>
<td>5) disability.mp</td>
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<td></td>
<td>7) mental disorder.mp. or Mental Disorders/</td>
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<td>8) psychiatr*.mp</td>
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<td>21) 21  limit 20 to yr=&quot;1980 - 2009&quot;</td>
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| **PsycINFO**  
| **(1980-2008)** | 1) mental retardation.mp. or Mental Retardation/  
| | 2) intellectual disability.mp  
| | 3) Developmental Disabilities/  
| | 4) handicap.mp  
| | 5) disability.mp  
| | 6) 1 or 2 or 3 or 4 or 5  
| | 7) mental disorder.mp. or Mental Disorders/  
| | 8) psychiatr*.mp  
| | 9) behavio*.mp  
| | 10) 8 or 7 or 9  
| | 11) 6 and 10  
| | 12) dual diagnosis.mp. or "Diagnosis, Dual (Psychiatry)"/  
| | 13) dual disorder.mp  
| | 14) 13 or 12  
| | 15) 11 or 14  
| | 16) prevalence.mp. or Prevalence/  
| | 17) occurrence.mp  
| | 18) rate.mp  
| | 19) 18 or 16 or 17  
| | 20) 19 and 15  
| | 21) limit 20 to yr="1980 - 2009"  
| **CINAHL** | 1) ("mental retardation") or (MH "Mental Retardation") or (MH "Mentally Disabled Persons")  
| | 2) "intellectual disability"  
| | 3) ("developmental disabilities") or (MH "Developmental Disabilities")  
| | 4) "handicap"  
| | 5) "disability"  
| | 6) (S5 or S4 or S3 or S2 or S1)  
| | 7) ("mental disorder") or (MH "Mental Disorders, Chronic") or (MH "Mental Disorders")  
| | 8) "psychiatr*"  
| | 9) "behavio*"  
| | 10) S9 or S8 or S7  
| | 11) S10 and S6  
| | 12) ("dual diagnosis") or (MH "Diagnosis, Dual (Psychiatry)")  
| | 13) "dual disorder"  
| | 14) ("dual diagnosis") or (MH "Diagnosis, Dual (Psychiatry)")  
| | 15) S13 or S12  
| | 16) S14 or S11  
| | 17) ("prevalence") or (MH "Prevalence")  
| | 18) "occurrence"  
| | 19) "rate"  
| | 20) (S18 or S17 or S16)  
<p>| | 21) (S19 and S15) |</p>
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<th>Database</th>
<th>Query</th>
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| EMBASE (1980-2008)      | 1) mental retardation.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name]  
|                         | 2) intellectual disability.mp.                                                           |
|                         | 3) developmental disabilities.mp.                                                         |
|                         | 4) handicap.mp.                                                                            |
|                         | 5) disability.mp.                                                                          |
|                         | 6) 4 or 3 or 5 or 1 or 2                                                                |
|                         | 7) mental disorder.mp.                                                                    |
|                         | 8) psychiatr*.mp.                                                                         |
|                         | 9) behavio*.mp.                                                                           |
|                         | 10) 9 or 7 or 8                                                                           |
|                         | 11) 6 and 10                                                                              |
|                         | 12) dual diagnosis.mp.                                                                    |
|                         | 13) dual disorder.mp.                                                                     |
|                         | 14) 13 or 12                                                                              |
|                         | 15) 11 or 14                                                                              |
|                         | 16) prevalence.mp.                                                                        |
|                         | 17) occurrence.mp.                                                                        |
|                         | 18) rate.mp.                                                                               |
|                         | 19) 17 or 16 or 18                                                                        |
|                         | 20) 15 and 19                                                                             |
|                         | 21) limit 20 to yr="1980 - 2009"                                                         |
| Global Health (1980-2008)| 1) mental retardation.mp. or mental retardation/ [mp=abstract, title, original title, broad terms, heading words]  
|                         | 2) intellectual disability.mp                                                             |
|                         | 3) developmental disability.mp                                                            |
|                         | 4) handicap.mp                                                                             |
|                         | 5) disability.mp                                                                           |
|                         | 6) 1 or 2 or 3 or 4 or 5                                                                  |
|                         | 7) mental disorder.mp.                                                                    |
|                         | 8) psychiatr*.mp                                                                           |
|                         | 9) behavio*.mp                                                                             |
|                         | 10) 7 or 8 or 9                                                                           |
|                         | 11) 6 and 10                                                                              |
|                         | 12) dual diagnosis.mp                                                                      |
|                         | 13) dual disorder.mp                                                                       |
|                         | 14) 12 or 13                                                                              |
|                         | 15) 11 or 14                                                                              |
|                         | 16) prevalence.mp                                                                         |
|                         | 17) occurrence.mp                                                                         |
|                         | 18) rate.mp                                                                               |
|                         | 19) 16 or 17 or 18                                                                        |
|                         | 20) 15 and 19                                                                             |
|                         | 21) limit 20 to yr="1980 - 2009"                                                         |
| AMED (1985-2008) | 1) mental retardation/ or mental retardation.mp  
|                  | [mp=abstract, heading words, title]  
|                  | 2) intellectual disability.mp  
|                  | 3) developmental disability.mp or Developmental disabilities/  
|                  | 4) handicap.mp. or Handicap/  
|                  | 5) disability.mp. or Disability/  
|                  | 6) 1 or 2 or 3 or 4 or 5  
|                  | 7) mental disorder.mp. or Mental disorders/  
|                  | 8) psychiatr*.mp  
|                  | 9) behavio*.mp  
|                  | 10) 8 or 7 or 9  
|                  | 11) 6 and 10  
|                  | 12) dual diagnosis.mp  
|                  | 13) dual disorder.mp  
|                  | 14) 13 or 12  
|                  | 15) 11 or 14  
|                  | 16) prevalence.mp  
|                  | 17) rate.mp  
|                  | 18) occurrence.mp  
|                  | 19) 18 or 16 or 17  
|                  | 20) 19 and 15  
| AARP Ageline (1980-2008) | 1) mental retardation.mp. [mp=abstract, descriptors, identifiers, title]  
|                          | 2) intellectual disability.mp  
|                          | 3) developmental disabilities.mp  
|                          | 4) handicap.mp  
|                          | 5) disability.mp  
|                          | 6) 4 or 3 or 5 or 1 or 2  
|                          | 7) mental disorder.mp  
|                          | 8) psychiatr*.mp  
|                          | 9) behavio*.mp  
|                          | 10) 9 or 7 or 8  
|                          | 11) 6 and 10  
|                          | 12) dual diagnosis.mp  
|                          | 13) dual disorder.mp  
|                          | 14) 13 or 12  
|                          | 15) 11 or 14  
|                          | 16) prevalence.mp  
|                          | 17) occurrence.mp  
|                          | 18) rate.mp  
|                          | 19) 17 or 16 or 18  
|                          | 20) 15 and 19  
|                          | 21) limit 20 to yr="1980 - 2009" |
All Evidence Based Medicine (EBM) Reviews – Cochrane Database of Systematic Reviews (DSR), ACP Journal Club, Database of Abstracts of Reviews of Effects (DARE), and Cochrane Central Register of Controlled Trials (CRCT) (1980-2008)

1) mental retardation.mp. [mp=ti, ab, tx, kw, ct, ot, sh, hw]
2) intellectual disability.mp
3) developmental disabilities.mp
4) handicap.mp
5) disability.mp
6) 4 or 3 or 5 or 1 or 2
7) mental disorder.mp
8) psychiatr*.mp
9) behavio*.mp
10) 9 or 7 or 8
11) 6 and 10
12) dual diagnosis.mp
13) dual disorder.mp
14) 13 or 12
15) 11 or 14
16) prevalence.mp
17) occurrence.mp
18) rate.mp
19) 17 or 16 or 18
20) 15 and 19

* search dates limited to first week of January 2009 in order to ensure that all articles until the end of 2008 were included.
APPENDIX B:

Systematic Review Data Extraction Sheet
Inclusion/Exclusion Criteria

(1) Is this study looking at the prevalence of psychiatric and/or behavioural conditions among individuals with an intellectual disability?
   YES -> Include  NO -> Exclude

(2) Is there a prevalence estimate that is restricted to individuals who are 16 years of age or older?
   YES -> Include  NO -> Exclude

(3) Is the study population-based?
   YES -> Include:
      o Administrative/registry population
      o General population
   NO -> Exclude

Participant Information

(1) Who was the study population? How was the study population sampled?

(2) What is the place of residence of the sample (setting, region, country)?

(3) Sample size:
   Response rate:

(4) Sample characteristics:

<table>
<thead>
<tr>
<th></th>
<th>Range</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
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<tr>
<td>Proportion</td>
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<tr>
<td>Gender – male</td>
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<td></td>
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<td>Level of ID</td>
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<td></td>
<td>Mild:</td>
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<tr>
<td></td>
<td>Severe:</td>
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</tbody>
</table>

(5) Intellectual disability: What is the cause of the intellectual disability?

How was the intellectual disability identified/diagnosed in the study?
(6) What was the definition of dual diagnosis/mental illness/behaviour problem?

(7) How were the psychiatric and/or behavioural conditions identified?

What assessment tools were used?

Who provided/collected the information?

Results

(1) What was the prevalence of psychiatric and/or behavioural conditions in the population?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatric conditions</td>
<td></td>
</tr>
<tr>
<td>Behavioural conditions</td>
<td></td>
</tr>
</tbody>
</table>

Methodological Quality Assessment

(1) Was this a representative sample of the study population?
   - Yes
   - No
   - Unsure

(2) Was the validity of the measurement tool/approach reported?
   - Yes
   - No
   - Unsure
APPENDIX C:

Summary of Articles in the Systematic Review
<table>
<thead>
<tr>
<th>Author (Date Published)</th>
<th>Geographical Location of Study</th>
<th>Sample Size</th>
<th>Condition Assessed</th>
<th>Assessment Type</th>
<th>Assessment Tool(s) Used</th>
<th>Result Reported</th>
<th>Study Quality: Representativeness of the sample to the underlying population</th>
<th>Study Quality: Validity of the assessment tool used</th>
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<tr>
<td>Bhaumik et al (2008)</td>
<td>Leicestershire and Rutland, UK</td>
<td>2,711</td>
<td>Behavioural</td>
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<td>Diagnostic Manuals</td>
<td>ICD-10</td>
<td>34%</td>
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<td>Clarke et al (1990)</td>
<td>Birmingham, England</td>
<td>1,825</td>
<td>Behavioural</td>
<td>Surveys of Service Recipients</td>
<td>Behaviour disorder definition</td>
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<td>Yes</td>
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<td>Clay &amp; Thomas (2005)</td>
<td>Marion County, Oregon, USA</td>
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<td>Psychiatric</td>
<td>Diagnostic Manuals</td>
<td>DSM-IV-TR</td>
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<td>Cooper et al (2007)</td>
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<td>Matthews et al</td>
<td>South/Mid Wales, UK</td>
<td>318</td>
<td>Behavioural</td>
<td>Standardized Assessment</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Psychiatric</td>
<td>Standardized Assessment</td>
<td></td>
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<td>Morgan et al</td>
<td>Western Australia</td>
<td>13,295</td>
<td>Psychiatric</td>
<td>Administrative Data</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<td></td>
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<td>Western Australia database</td>
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<tr>
<td>Smith et al</td>
<td>Leicestershire, UK</td>
<td>2,202</td>
<td>Behavioural</td>
<td>Standardized Assessment</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Taylor et al</td>
<td>Northeast England</td>
<td>1,155</td>
<td>Psychiatric</td>
<td>Standardized Assessment</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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</table>
APPENDIX D:

Reference List of Articles Chosen for Systematic Review


APPENDIX E:

Questions Selected From CCHS (2005), PALS (2006), and SAID-SEO (2008/09)
<table>
<thead>
<tr>
<th>Data Source</th>
<th>Intellectual Disability</th>
<th>Mental Illness</th>
<th>Demographics</th>
<th>Mental Health Care Utility</th>
</tr>
</thead>
</table>
| Canada Community Health Survey, Cycle 3.1 (2005) | Do you have autism or any other developmental disorder such as Down’s syndrome, Asperger’s syndrome or Rett syndrome? (Chronic Conditions section question 321) | - Question 271: Do you have schizophrenia?  
- Question 280: Do you have a mood disorder such as depression, bipolar disorder, mania or dysthymia?  
- Question 290: Do you have an anxiety disorder such as a phobia, obsessive compulsive disorder or a panic disorder?  
- Question 341: Do you have an eating disorder such as anorexia or bulimia? | Sex: male, female  
Age: exact age  
Geography: provincial | In the past 12 months, how many times have you seen, or talked on the telephone, about your physical, emotional or mental health with:  
- a family doctor or general practitioner? (HCU_Q02A)  
- any other medical doctor (such as surgeon, allergist, orthopedist, gynaecologist, or psychiatrist)? (HCU_Q02C)  
- a social worker or counsellor? (HCU_Q02H)  
- a psychologist? (HCU_Q02I) |
| Participation and Activity Limitation Survey (2006) | Has a doctor, psychologist or other health professional ever said that you (…. ) had a developmental disability or disorder? These include, for example, Down syndrome, autism, Asperger syndrome, mental impairment due to a lack of oxygen at birth, etc. (Section Q – Developmental Filter question Q1) | Do you (Does (…. ) have any emotional, psychological or psychiatric conditions that have lasted, or are expected to last, 6 months or more? These include phobias, depression, schizophrenia, drinking or drug problems and others. (Section R – Emotional Filter question RI) | Sex: male, female  
Age: exact age  
Geography: provincial | In the past 12 months, how often have you (has …. ) seen or talked about (a) your (his/her) physical, emotional or mental condition, with a physician (including general practitioners and specialists)? (Section DD – Health with Everyday Activities question DD1) |
| SAID-SEO (2008/09)\(^3\) | Geographic Registry in Intellectual Disability | Does (name of person with ID) currently have a diagnosed psychiatric illness or behaviour disorder? | Sex: male, female  
Age: exact age  
Geography: SE Ontario | Is the (name of person with ID) currently receiving any services to help with a psychiatric or behavioural condition? |

\(^1\) Statistics Canada, 2005a;  
\(^2\) Statistics Canada, 2006b;  
\(^3\) Ouellette-Kuntz et al, 2007b
APPENDIX F:

Ethics Approval
QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

November 26, 2008

Ma. Iwona Anna Bielska
Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON K7M 8A6

Dear Ms. Bielska,

Study Title: Using population health databases to measure the provision of services and the prevalence of psychiatric and behavioural conditions in individuals with an intellectual disability

Co-Investigators: Ms. H. Ouellette-Kuntz, Dr. D. Hunter

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair's signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following list of ethics requirements you must fulfill over the course of your study:

➢ Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. (see http://www.queensu.ca/vpr/reb.htm).

➢ Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.

➢ Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

➢ Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair's signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

[Signature]
Chair, Research Ethics Board

Date

[Signature]
Date

Study Code: EPID-281-08

➢ Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete.