Psychotropic Medication Use by Adults with Intellectual Disabilities
Living in Community Settings

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Abstract

This study examined the variables related to psychotropic medication use among 73 adults with intellectual disabilities living in community residential settings in Ontario, Canada over a one-year period based on staff reports. Despite only 16% percent having a documented psychiatric diagnosis, 84% of these individuals were receiving psychotropic medications, and 74% were receiving two or more psychotropic medications (polypharmacy). Anti-psychotics, anti-anxiety medications, and anti-convulsant medications were the most frequently reported drug classes. While problem behaviour was reported for 60% of the participants, only 33% had a formal behaviour plan. There was a significant relationship between the reported number of problem behaviours and the reported number of prescribed psychotropic medications. Reported medication reviews did not adhere to the Canadian ‘Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities’ (Sullivan et al., 2006). Results, based on staff reports, suggested incongruence with recommended best practices, and raised concern about over-reliance on psychotropic medication with these individuals.

Keywords: intellectual disabilities, psychotropic medication, problem behaviour
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Psychotropic Medication Use in Adults with Intellectual Disabilities

Living in Community Settings

Individuals with intellectual disabilities (ID) are at an increased risk to develop mental health issues and/or behavioural problems across the lifespan (Sturmey, Lindsay, Didden, 2007). Intellectual disability is the current term used to describe the same group of individuals who have been previously referred to as having a 'developmental disability' or 'mental retardation' (AAIDD, 2011). Compared to the general population, the prevalence of psychiatric disorders in individuals with intellectual disabilities is approximately 2–4 times greater (Borthwick-Duffy, 1994; DM-ID, 2007; Wachtel & Hagopian, 2006). Research shows that individuals with ID are frequently prescribed psychotropic medications to control problem behaviours without the presence or diagnosis of a mental illness (Bouras, 1999; Grey & Hastings, 2005; Matson, Bamburg, Mayville, et al., 2000). Problem behaviours are a major concern for families, caregivers, and professionals in the field due to the negative impact behaviours can have on an individual's development and care. Severe problem behaviours can lead to decreased social opportunities, interfere with learning, and create economic challenges due to the high levels of needed supports (Wachtel & Hagopian, 2006). These individuals with ID and a mental health issue, psychiatric diagnoses, or severe problem behaviours are referred to as having a 'dual diagnosis', (Sturmey, Lindsay, Didden, 2007). There is a considerable amount of research with people who have dual diagnoses, and the use of psychotropic medications (daily and as needed) as a first line management approach is evident, although there are relatively few methodologically sound drug efficacy studies that include people with ID in their samples (Oliver-Africano, Dickens, Ahmed, Bouras et al., 2010; Tyrer et al., 2008). Furthermore, the
application of relevant research findings to actual clinical practice remains a challenge (Barnhill, 2008; Matson & Neal, 2009).

**Purpose of Study**

This study addressed the current research and literature gaps by examining the related variables and rationales for psychotropic medication use (daily & as needed psychotropic use) in an Ontario based sample of individuals with ID. The study was a retrospective analysis, which examined data collected by residential agency managers from an existing database of information pertaining to 73 adults with a primary diagnosis of ID living in Ontario. At present, there is limited information in Canada, on the use of psychotropic medications for individuals with ID who are living in community residential settings or group homes (Lott et al., 2004), although some previous studies have reviewed psychotropic drug use in Asian, European and American population samples (Aman, Sarphare, Burrow, 1995; Bisconer, Sine, Zhang, 1996; Holden & Gitlesen, 2004; Lott, McGregor, Engelman et al., 2004; Stolker et al., 2001). The empirical evidence and rationales for the use of pharmacological interventions to address both problem behaviour and psychiatric disorders were reviewed (Grey, & Hastings, 2005; Sturmey, Lindsay, Didden, 2007; Wachtel & Hagopian, 2006).

**Significance of Current Study**

There is limited information within the literature on the prevalence of psychotropic prescribing practices in Canadian studies of individuals with ID living in the community. Existing research has not comprehensively examined individual characteristics, the presence, or absence of behaviour problems, prescribed as needed psychotropic medication use (PRN), rationales for different drug use, most common poly-prescribing combinations, or the other
therapeutic interventions in place in combination. Studies have not compared prescribing and monitoring practices to the standards of practice that are set forth in regions or countries of interest.

Understanding the patterns of psychotropic drug use could help residential support agencies develop ethical guidelines and monitoring processes, and ultimately work towards adhering to the 'Consensus Guidelines for Primary Health Care of Adults with ID', CME (2006). Some of the anticipated benefits of this study include: (a) a heightened understanding of the prevalence and prescribing practices of psychotropic medications in this Ontario ID/DD sample; (b) the affiliated community agency will be provided with more meaningful information to: enable their effective program evaluation, improve tracking, monitoring, and review processes of medication use; (c) there will be a greater understanding of risk factors or predictors of psychotropic drug use in the individuals supported by the agency. These outcomes will also contribute to the field of developmental disabilities research in the areas of challenging/problem behaviours, psychotropic medication use. The findings of this study are expected to help improve services for individuals with ID and ultimately to positively impact participants’ quality of life. This study will help bridge the gap between current research and practice in community agencies through the dissemination of the findings at the end of the study.

**Literature Review**

Throughout this paper the term ‘Intellectual Disability’ (ID) will be used to describe the diagnosis of individuals who have been referred to as having a Developmental Disability, (DD) or Mental Retardation, (MR) in the past (AAIDD, 2010). An ID is characterized by significant impairment in adaptive and intellectual functioning, expressed in practical, conceptual, and social skills, with an onset and diagnosis prior to the age of 18 years (AAID, 2010). The
following literature review will cover research and information in the areas of ID and mental health issues, problem behaviours, treatment of problem behaviours, psychotropic medications, efficacy and effectiveness research, prevalence studies, and consensus guidelines for the use of psychotropic medications.

**Intellectual Disabilities and Mental Health Issues**

Individuals with ID are identified to be at a greater risk to experience a psychiatric disorder or mental health issue compared to the general population (Chaplin, 2004; DM-ID, 2007; La Malfa, Campigli, Bertelli, Mangiapane, et al., 1997; Morin, Cobigo, Rivard, Lepine, 2010). The risk factors (vulnerabilities) involved in the development of psychopathology in these individuals include: specific genetic syndromes; limited coping and communication skills; and behavioural phenotypes, which may include elements of psychiatric pathologies and aberrant (problem) behaviours (Bouras & Jacobson, 2002; Griffiths & King, 2004; Oliver & Hagerman, 2007; Sturmey, Lindsay, Didden, 2007; Wachtel & Hagopian, 2006). The rates of psychiatric illness within this population are reported to range widely from 10% to as high as 80% (Verhoeven & Tuinier, 1997; Wachtel & Hagopian, 2006). This large range reflects ongoing challenges with accurate diagnoses of mental health issues (Morin et al., 2010). Historically, there has been a lack of psychometrically sound instruments to accurately diagnose mental health disorders (Gardner, 2000). This has contributed to misdiagnosis, under-diagnosis, behavioural issues being managed with inappropriate pharmacological interventions, and or psychiatric or bio-medical issues being addressed with behavioural interventions alone (Gardner, 2000).

Increases in problem behaviours, such as, aggression, self-injury, or property destruction are frequently the preceding factor for a psychiatric referral (DM-ID, 2007). One of the key
issues impeding accurate psychiatric diagnostic processes is the lack of experienced medical professionals dealing with individuals with ID, resulting in a decreased awareness, sensitivity, and ability to differentiate the psychiatric disorder from the disability itself (Gardner, 2000). Other diagnostic challenges are: the tendency of people with mild and moderate ID to try and hide their disabilities "cloak of competence", (Edgerton, 1967); difficulties accurately describing their experiences related to expressive and receptive language deficits; a tendency to tell an interviewer what they want to hear and thus answer questions falsely (referred to as "acquiescence bias") (DMID, 2007); challenging behaviour being attributed to the ID rather than a psychiatric disorder "diagnostic overshadowing", (Reiss, Levitan & Syszko, 1982); and assumptions that people with ID will have different symptoms of psychiatric disorders "psychosocial masking" (Sovner, 1986). The more commonly reported psychiatric disorders within the ID population include depressive disorder; anxiety disorder; bipolar affective disorder; conduct disorder; obsessive-compulsive disorder; and impulse control disorder (La Malfa, et al., 1997; Rojahn, J., et al., 2003; Verhoeven & Tuinier, 1997).

Assessment tools that enable more accurate diagnoses of mental health issues are now available, although their reliability and validity varies (Pomeroy, 2006). The difficulty interpreting the relative contribution of either the developmental disability or the mental health issues on the clinical presentation of an individual still occurs (Antochi, Stavrakaki, Emery, 2003). However, several assessment tools have been modified and created to utilize more objective and behavioural diagnostic criteria. The Diagnostic Criteria for Psychiatric Disorders for Adults with Learning Disabilities/Mental Retardation, DC-LD, (Royal College of Psychiatrists, 2001) was developed to provide operational definitions for each of the criteria needed to determine the presence of psychiatric issues (DMID, 2007). The Diagnostic Manual
for Intellectual Disability (DM-ID) was recently published in 2007, and included objective
behavioural indices in order to help facilitate more objective diagnosis of mental health issues
experienced by people with ID and to improve research methodology (e.g., selection) in the area
of dual diagnosis, and to increase appropriate treatment selection based on assessment outcomes
(Ruedrich et al., 2008). The longstanding diagnostic inconsistencies among professionals, has
impacted research conducted in the dual diagnosis field with regard to research participants
inclusion or exclusion, and treatment selection (Antochi, Stavrakaki, Emery, 2003). The
treatment of psychiatric disorders in persons with ID ought to at least be as stringent as treatment
of the general population (Deb, 2006). Treatment guidelines for the use of psychotropic
medications for individuals with dual diagnoses must be updated and modified on an ongoing
basis to increase the provision of the most effective evidence-based treatments. It is also
important that clinicians understand that problem behaviours are not all symptomatic of existing
mental health issues.

**Intellectual Disabilities and Problem Behaviours**

‘Problem’ or ‘challenging behaviour’ are umbrella terms used to describe a range of
disruptive or dangerous behaviours in the ID population (Matson & Neal, 2009). Some
examples of problem behaviours are: temper tantrums, verbal and physical aggression,
screaming, property damage, and destruction, self-injurious behaviour (i.e. self-hitting, self-
biting, and skin picking), over activity, (Heyvaert, Maes, Onghenaël, 2010). Because behavioural
problems are prevalent in individuals with ID this creates many challenges throughout the
lifespan (Mahan, Holloway, Bambug, Hess, 2010; Sturmey, Lindsay, Didden, 2007; Wachtel &
Hagopian, 2006). The impact of problem behaviours on the emotional, social, physical,
educational, and economic aspects of a person’s life can lead to reduced opportunities for community involvement, educational placements, or habilitative programming (Heyvaert, Maes, Onghena1, 2010; Wachtel & Hagopian, 2006). The prevalence of behavioural problems has been reported to range from 10–31% for self-injury, 7–30% for property destruction, and 2–28% for aggression (Wachtel & Hagopian, 2006). Behavioural problems have also been found to be more common in individuals with more severe ID or ASD, which may relate to a decreased ability to communicate or use effective coping strategies (McClintock, Hall & Oliver, 2003).

Neurological models of behaviour attempt to explain the possible etiologies of some problem behaviours. These explanations underlie the use of psychotropic medications to address specific behaviours by associating neurotransmitter activity in the brain and the pathophysiology of some behaviour (Matson, Mayville, Pinkston, et al., 2000; Santosh, & Baird, 1999; Schroeder et al., 1998). Self-injurious behaviour has three proposed neurological models: the opioid hypothesis; the dopamine hypothesis; and the serotonergic hypothesis (Baumeister & Sevin, 1990; Schroeder et al., 1999; Symons, Thompson, Rodriguez, 2004). The dopamine (DA) depletion hypothesis was developed when post mortem brain analysis revealed that individuals with Lesch-Nyhan Syndrome (~100% prevalence of SIB) showed reduced indices of dopamine functions (Baumeister & Sevin, 1990). This hypothesis expects that DA antagonist drugs would inhibit SIB. However, since research conducted in this area is methodologically flawed, this hypothesis remains inconclusive (Baumeister & Sevin, 1990). The opioid hypothesis posits that two mechanisms of action are involved in SIB: a decreased sensitivity to pain, and an addiction to the release of endogenous opioids (Baumeister & Sevin, 1990; Matson, Mayville, Pinkston, et al., 2000; Santosh, & Baird, 1999; Schroeder et al., 1999). If self-injury is in fact influenced or maintained by the release of endogenous opioids, then an opiate antagonist, which blocks opioid
receptors, would be expected to attenuate SIB (Symons, Thompson, Rodriguez, 2004). However, there is only limited literature supporting the efficacy of Naltrexone (opioid antagonist) to decrease self-injurious behaviour (Schroeder et al., 1999; Symons, Thompson, Rodriguez, 2004).

Animal research has also implicated involvement of the serotonergic system with problem behaviours, such as, aggression and self-injury (Thompson & Symons, 1999). A decreased level of serotonin (5-HT) in animal brains was related to the presence of aggressive or self-injurious behaviours (Thompson & Symons, 1999). Therefore, the application of a psychotropic drug to increase the level of serotonin would be expected to decrease these behaviours. However, there is no conclusive evidence supporting this hypothesis.

The proposed neurological model for general destructive behaviours loosely involves the dopaminergic system. Studies indicated that dopamine (DA) modulation, primarily the sedation effects of DA acting drugs (antipsychotics), decreased destructive behaviours in some cases (Thompson & Symons, 1999). The administration of antipsychotic drugs was hypothesized to reduce the reinforcer effectiveness (positive or negative) that may be involved in maintaining destructive behaviours (Thompson & Symons, 1999). Although these models provide theoretical hypotheses about modifiable relationships between brain and behaviour, they do not clearly indicate causal relationships nor do they consider other possible contributing factors, such, as operant motivations. Although it is appropriate to consider neurological models of behaviour before selecting a pharmacological interventions, neurological models on their own do not sufficiently explain or address all the complex factors which may be involved in the origin or maintenance of problem behaviours (Barnhill, 2008; Matson & Neal, 2009).
Behaviours can also be learned and maintained through interactions with the physical and social environment (Cooper, Heron, Heward, 2007). Behaviours that are learned or maintained through reinforcement contingencies are referred to as operant behaviours. A person's ability to effectively communicate their needs, deficits in adaptive, social, or coping skills, underlying mental health issues, genetic syndromes, and the support qualities of their living environments can influence behaviour (Cooper, Heron, Heward, 2007; Sturmey, 1995; Gardner, 2002). Antecedent stimuli can also act as triggers for problem behaviour or they can act as environmental conditions or setting events that affect the likelihood of the occurrence of behaviour (Horner, Day & Day, 1997). A functional behavior assessment (FBA) is an assessment technique which can be used to form a hypothesis about the "function or purpose" of a specific behavior (Cooper, Heron, Heward, 2007; Herzinger & Campbell, 2007). The outcomes from FBA's can be used to facilitate the development of appropriate treatment interventions to meet the communicative and functional needs of individuals with problem behaviours (Herzinger & Campbell, 2007).

A thorough bio-psycho-social assessment of an individual prior to treatment planning would help identify any root causes or influences on an individual's behaviour or clinical presentation that may be related to a medical, psychiatric, or learning based issues (La Malfa, Lassi, Bertelli, Castellani, et al., 2006; Tsouris, 2009). A bio-psychosocial approach would also help prevent over-attribution of behaviour problems as markers of a psychiatric disorder, or behaviour problems being considered a part of a disability when in fact there may be a psychiatric component (La Malfa, Lassi, Bertelli, Castellani, et al., 2006). A thorough assessment would also assist to identify any behavioural problems, which may serve an operant function (La Malfa, Lassi, Bertelli, Castellani, et al., 2006). A better understanding of the root
causes of problem behaviour would help a clinician justify their treatment decisions, or to use, or not use, a psychotropic medication to decrease undesirable behaviours. This would also decrease the chance that psychotropics medications would function as a chemical restraint (Matson et al., 2000).

**Psychotropic Medications and Intellectual Disabilities**

As early as the 1950s, psychopharmacological drugs were prescribed to individuals with ID, primarily for their general sedative effects and in the absence of available research on efficacy (Schroeder et al., 1998). The use of psychotropic medication to treat individuals with ID became even more prevalent during the 1970s and 80s (Schroeder et al., 1998). Historically, research in the area of ID and psychopharmacology was lacking due to funding issues and legislation protective of this population (Schroeder et al., 1998).

**Classes of Medication**

There are several categories of psychotropic medications used to address psychiatric disorders or problem behaviours in individuals with ID. The general goal of psychotropic interventions are the altering of neurological systems in order to decrease undesirable symptoms or mood states, to modulate neurotransmitter activity, and to alter central nervous system functions (Pointedexter, 2002). The majority of psychotropic medications being prescribed for individuals with ID fall into the following medication classes: neuroleptics (antipsychotics); anti-epileptics; antidepressants; anxiolytics and sedatives; mood stabilizers; opioid blockers; and beta-adrenergic blockers (Kern, 1999, p.103; NIMH, 2010). The most common psychopharmacological drugs from each class, the suspected neurological effects, and common reasons for administration are presented in Appendix A.
Rationales for Psychotropic Medication Use

The rationales for the use of pharmacological interventions by persons with ID and psychiatric disorders has to date been explained by the research on the neurotypical mental health population (Matson et al., 2000; Spreat, Conroy, Jones, 1997). In the treatment of mental health issues there is evidence that psychotropic medications can reduce underlying adverse mood states, and thereby decrease the impact of external antecedent or triggering conditions (Deb et al., 2007; Gardner, 2008). However, there is ongoing concern that the variability in neurological, cognitive, or behavioral impairments, makes individuals with ID more susceptible to adverse side effects (Mahan, Holloway, Bamburg, Hess et al., 2010). These neurological and cognitive differences in persons with ID question the premise that the effectiveness of psychotropic medication can be directly predicted from the effects seen in the neurotypical population (Baumeister & Sevin, 1990). Some literature has shown successes in treating symptoms specifically related to psychiatric disorders, however, individuals with ID are most frequently prescribed psychotropic medications to control problem behaviours (reference), and often without the actual presence or diagnosis of a mental illness (Bouras, 1999; Grey & Hastings, 2005; Matson, Bamburg, Mayville, et al., 2000). Research suggests that when psychotropic medications are used in the absence of a mental health issues they can sometimes decrease problem behaviours, however, they may actually be suppressing behaviour and thereby interfere with the identification of other possible root causes of behaviour, such as, deficits in communication or other skills (Allen, 2008; Brylewski & Duggan, 1999; Tyrer, 2008, Kuijper et al., 2010). Nevertheless, the use of pharmacological interventions for individuals with ID remains widespread (Nottestad & Linaker, 2003; Deb et al., 2009).
Treatment of Problem Behaviours

The gradual closure of residential institutions over the past three decades has brought to light the importance of finding and implementing effective and sustainable community based treatment strategies for individuals with ID (Burd, Williams, Klug, Fgelstad, 1997). The use of psychopharmacological drugs has continued to be prevalent, irrespective of assessment challenges or the presence or absence of a psychiatric diagnosis (Sturmey, Lindsay, Didden, 2007). Problem or severely disruptive behaviours can be difficult to address in some community settings, which may have limited resources (Wachtel & Hagopian, 2006). Researchers have suggested that the high rates of psychotropic reliance may be related to medical services being more available and accessible than alternative or psychological services. Moreover some researchers assert that in place of long-term therapeutic intervention, practitioners continue to address problem behaviours in a reactive way (La Malfa, et al., 2006; Matson & Minshawi, 2007; Matson, Mayville, Pinkston, et al., 2000; Matson et al., 2000; Santosh, & Baird, 1999; Tsakanikos, Costello, Holt, et al., 2007).

Currently, both pharmacological and behavioural interventions are the two dominant treatment approaches used to address the problem behaviours of individuals with ID (Gardner, 2000; Matson & Neal, 2009; Matson & Wilkins, 2008). Both approaches have been found to have merit in different contexts, although they are not often used cooperatively or as part a multidisciplinary plan (Matson & Wilkins, 2008). In fact the implementation of either pharmacological or behavioural interventions for problem behaviours have been found to directly relate to the place of primary residence, as well as, the availability or accessibility of a psychiatrist experienced in working with individuals with ID, or appropriate behavioural services (Jacobson & Bouras, 2002; Matson & Wilkins, 2008). Limited accessibility and resources can
decrease the chances that individuals will receive the most appropriate evidence based treatment (Bradley & Cheetham, 2010). Applied Behaviour Analysis utilizes functional assessment methodologies to examine operant explanations for behaviour (functions) (Hanley, Iwata, McCord, 2003). Research has shown that behavioral interventions based on functional assessment results can effectively decrease rates of problem behavior in persons with ID (Carr & Durand, 1985; Matson, Copper, Malone, Moskow, 2008; Heyvaert, Maes, Onghena1, 2010).

There are also a few studies that reported some efficacy of pharmacological interventions for the management of problem behaviours, however, most studies (see next section) are methodologically flawed and thus their claims are weak at best (Deb et al., 2007; La Malfa, et al., 2006; Matson et al., 2000; Matson et al., 2003; Matson & Neal, 2009).

**Off Label Use**

Research has also revealed that individuals with ID are often prescribed drugs for off-label indications (Baumeister, Sevin, King, 1998, p. 147). ‘Off Label’ medication use refers to the prescribing of drugs for issues outside the marketing or licensed authorization, or for a dose in excess of the marketing authorization, such as, an anti-psychotic being given to address a depressive disorder, despite literature indicating the first-line use of an antidepressant (Haw & Stubbs, 2005). Essentially, what this means is that many psychotropic drugs have not been examined for risks, benefits, efficacy, or side effects for these ‘off-label’ uses (Haw & Stubbs, 2005). Although off-label prescribing has been described as a common practice within the field of psychiatry and the typical population, this rationalization does not seem ethical for more vulnerable or special groups, such as, children and people with ID (Haw & Stubbs, 2005). In addition, getting informed consent from patients to take a drug that has been prescribed for an off-label reason is imperative, and this can be a challenge with individuals with ID who may
have communication issues or a limited capacity to understand the meaning of off-label and the idea of a risk/benefit ratio (Haw & Stubbs, 2005). In a 2005 study conducted on 56 in-patients from an ID division of a charitable hospital with mild ID and mental illness, 46% were found to be receiving a minimum of one off-label psychotropic medication (Haw & Stubbs, 2005). The most prevalent rational for the off-label prescribing was reported to be the reduction of aggression, arousal, behavioural disturbance, and mood stabilization (Haw & Stubbs, 2005). These off-label uses suggest that some medications are being used for their secondary sedative effects rather than the intended primary therapeutic effects (Allen, 2008). The field of ‘Dual diagnosis’ would benefit from more methodologically sound research, to specifically investigate the effectiveness of psychopharmacological treatments within this vulnerable population.

Side Effects

There are many known side effects of psychotropic medications. Detecting side effects is difficult in individuals with ID because they may not be able to effectively communicate their psychological states, they may not be aware of the side effects to look for, drug related experiences and their disability may also mask some signs of toxicity (Deb et al., 2009; Mahan, et al., 2010; Matson et al., 2000; Stavraki et al., 2002). For example, individuals may also have a hard time expressing unpleasant or adverse effects to their caregivers, or stereotypic behaviours may be misinterpreted as part of a disability rather than a drug-induced movement (Stavraki et al., 2002). It can also be difficult to measure mood changes, or the worsening of other problem behaviours, following medication administration (Valdovinos, et al., 2005). Nonetheless side effects are an important consideration when using psychotropic drugs. The careful monitoring of side effects is recommended (Matson, Rivet, Fodstad, 2008). All medications carry both risks and benefits, therefore, the intended therapeutic impact or outcome may be influenced, negated,
or compromised by secondary effects of the medication. Side effects can potentially impact:
medication non-compliance, increased behaviour problems, quality of life, impaired cognitive
functioning, interference with learning (Kalachnik, 1999).

The development of the newer classes of atypical antipsychotic medications and
antidepressants, Selective Serotonin Reuptake Inhibitor, (SSRIs), has reduced the associated side
effect profiles (Ruedrich et al., 2008; Singh et al., 2005). However, currently they are no
accepted standardized methods recommended to most effectively recognize and monitor side
effects in this population and thus this area warrants further attention and guidelines. Without
careful medical or program monitoring systems in place, there is a high risk that any short-term
benefits of psychotropic medications can easily become long-term treatments or management
approaches (Manchester, 1993). The ‘International Guide to Prescribing Psychotropic
Medications for Problem Behaviours’ has also recommended that consideration be given to the
impact of the medication on the quality of life of the treated individual, to ensure it is ethical to
continue (Deb, 2007). It is important to clarify who will be monitoring for any negative side
effects of the medications and how the monitoring will be done (Deb, 2006). The ability to
effectively recognize and monitor side effects in this population remains a challenge.

Psychotropic Medications: Efficacy and Effectiveness Research

In clinical research, the accepted ‘Gold Standard’ research design is a double-blind
randomized controlled trial (RCT). Standards propose that efficacy data refer to double-blind
and placebo controlled studies that have a random assignment of participants to the treatment
conditions; including both baseline and reversal phases (ABAB designs) when ethically possible;
and that they utilize single and within subject designs, as well as, direct objective measures of
behaviour change and side-effects (Baumeister & Sevin, 1990; La Malfa, et al., 2006). The term polypharmacy or poly prescribing can either describe the prescribing of more than one psychotropic medication for a particular indication, i.e. a behaviour problem or the prescribing of more than one psychotropic medication to an individual (Deb, 2006).

In their 2006 review, La Malfa et al. examined 195 studies on pharmacology and ID for methodological rigour and efficacy reports about psychotropic medications. They found that efficacy reports of the pharmacological interventions for problem behaviour were primarily based on case reports, consensus documents, case reviews, expert or consensus opinions, and general reviews of literature; only 21 of the 195 studies utilized RCTs with follow-up. Many studies also neglected to report whether there were any considerations about the underlying causes (psychiatric) or functions of problem behaviours before pharmacological interventions were initiated (Deb et al., 2007).

The main methodological problems identified with published clinical studies in the area of pharmacology and ID, were: a lack of objective measures to evaluate the efficacy of the medications; heterogeneous samples and outcomes measures, inadequate reporting of negative side-effects; and the absence of behavioural assessments prior to medication administration (Dinca, Paul, Spencer, 2005; Matson & Neal, 2009; Oliver-Africano, Dickens, Ahment, 2010). There is also a limited body of data concerning the effects of psychotropic medications across all sub-classifications of pervasive developmental disorders and ID, across different age categories, looking at short, medium, and long-term effects, and the overall impact on the quality of life of the treated individuals (Dinca, Paul, Spencer, 2005). There are also ongoing recruitment challenges related to participant accessibility, consent/assent issues, heterogeneity of participants, and attitudes toward treatment (Dinca, Paul, Spencer, 2005; Oliver-Africano,
Dickens, Ahment, 2010). Since the studies on the treatment of problem behaviour or mental health issues with psychotropic medications in individuals with ID have these methodological constraints, it is imperative that the findings are interpreted with caution.

Recently there have been increased efforts within the scientific and medical communities to completed more RCT efficacy studies in the area of psychotropic medications for individuals with ID (Oliver-Africano, Dickens, Ahment, 2010). However, results from these studies continue to be mixed. For example, in 2005 and 2006 a few RCT studies were shown to support the efficacy of Risperidone for the management of aggression or general problem behaviours in both children and adults with ID (Deb, 2006; Gagliano, Read, Thorpe, et al., 2005; Grey, & Hastings, 2005). At that time, Haloperidol (conventional antipsychotic) was still identified as the most widely prescribed antipsychotic drug (La Malfa, et al., 2006). Since then, two RCT studies comparing the effects of Risperidone, Haloperidol, and placebo, in the treatment of aggressive behaviour in individuals with ID found that all three agents had a reduction in aggression at 4 weeks, however, the placebo group had the largest decrease in aggressive behaviours and was the most cost effective (Tyrer et al., 2008; Tyrer, Oliver-African, Romeo, Knapp, 2009).

In a 2009 review, Matson & Neal examined 56 drug efficacy studies with people with ID and problem behaviours. Only 23 of the studies met the criteria of double blind, placebo controlled procedures, and only 12 met the additional criteria of random assignment. The efficacy results of the 12 double blind, placebo controlled and randomly assigned studies were mixed and thus inconclusive. Furthermore, the stringent studies examining the effectiveness of psychotropics on behaviour reduction (i.e. RCT + more objective behavioural change measures), tended to report less effects or ‘no change’ when compared to placebo (Matson & Neal, 2009; Tyrer et al., 2008). Thus it is becoming increasingly clear that studies with more rigorous
experimental designs and objective behavioural outcome measures are less likely to support psychotropic medications as efficacious for the treatment of problem behaviours in persons with ID (Matson & Neal, 2009).

Research clearly shows that there is currently no drug specific evidence to recommend the use of one particular medication over another for problem behaviours in persons with ID (World Psychiatric Association, 2009). Additionally, most psychotropic drugs are not officially licensed or approved to treat challenging behaviours (Deb et al., 2007). Also the large number of different psychotropic medications makes it difficult to make general efficacy claims due to the lack of testing done with each different medication. Research findings from one particular medication or medication class do not necessarily generalize to other psychotropic medication in the same class. Although methodological rigor has improved, there continue to be individual recruitment issues, a lack of efficacy studies on the wide variety of different medications, including functional assessments and objective outcome measures, with long treatment follow ups, clear reporting of related adverse side effects (Oliver-Africano, Dickens, Ahmed, Bouras, et al., 2010; Matson & Neal, 2009; Tyrer et al., 2008).

In conclusion, the mixed results, the diverse number of different psychotropic medications, and the few studies with rigorous control procedures highlight the importance of exercising caution with regard to the use of psychotropic medications for the management of problem behaviours in persons with ID (Matson & Neal, 2009). Although the methodological rigor of some recent studies has improved, there continues to be a challenge with individual recruitment, a lack of follow ups, inconsistent reporting of adverse side effects, and short experimental trials (Matson & Neal, 2009; Oliver-Africano et al., 2010). Literature continues to indicate that problem behaviours are consistent predictors for the use of psychotropic medications in adults
with ID despite the above-mentioned concerns (Aman, Sarphare & Burrows, 1995; De Kuijper et al, 2010; Holden & Gitlesen, 2004; Singh, Ellis & Wechsler, 1997; Tsakanikos, Bouras, Costello, & Holt, 2007).

Prevalence of Psychotropic Medication Use

The prevalence of psychotropic medication use in individuals with ID who are living in community settings, ranges widely. An American community-based study conducted in 1995 reported that 27% of 1101 individuals with ID living in a group home, were prescribed one or more psychotropic drugs for behavioural or emotional disorders, and 12% were prescribed between two to five drugs (Aman, Sarphare, Burrow, 1995). The researchers also made several interesting discoveries. They found no relationship between existing diagnoses and medication use from the related drug treatment class, i.e. depression → anti-depressant medication, no correlation between age and prevalence of psychotropic medications, and no gender effects for total psychotropic use. Individuals with more severe levels of ID were found to receive less psychotropic medications. They also reported that participants with diagnosed seizure conditions received less psychotropic medications prescribed for behaviour control (although many had psychotropic medications prescribed for seizure control).

Examination of rationales to use the drugs revealed that many of the drugs were used to address concerns or symptoms for which the drug use had not been established or approved empirically. Aman et al. concluded that there was no empirical support for the safe or effective use of anti-psychotics/neuroleptics for these behavioural issues. Burd, Williams, Klug, Fjelstad, et al. (1997), found that 38% of 1384 individuals with ID had psychotropic medications prescribed and 11% had more than one psychotropic prescribed. They also found a significant
relationship between the use of polypharmacy and psychiatric diagnoses. Spreat, Conroy, Fullerton, & Bodfish (2004) conducted a longitudinal survey of psychotropic medication use in individuals with ID between 1994 and 2000. They found that in 2000, 35.4% of the 3187 individuals with ID were receiving psychotropic medications. An examination of the classes of prescribed psychotropics showed that approximately 20% of adults were being prescribed antipsychotics, 15.8% antidepressants, and 11.1% anxiolytics.

Another American study conducted in 2004 examined the longitudinal prescribing practices for psychoactive medications for 2344 persons with ID over a 17-month period, using pharmacy records (Lott, McGregor, Engelman, Touchette et al., 2004). Their results showed that 52% of all prescriptions were for psychoactive medications. Antipsychotics, antidepressant and anticonvulsant medications were revealed to be the most commonly filled prescriptions. Sixty-two percent of the individuals in their study were prescribed more than one psychoactive medication and 36% received three or more psychoactive medications (Lott, McGregor, Engelman, Touchette et al., 2004). Their study did not report any comparative information regarding the rationales for drug prescriptions.

Studies conducted in the Netherlands by van Schrojenstein Lantman-de Valk et al., (1995) and Stolker et al., (2002) found the prevalence of psychotropic medication use to be 24% and 17%, respectively, for individuals with ID living in group homes. Stolker et al., (2002) also noticed that 17% of the 573 individuals identified as having ‘problem behaviours’, were prescribed multiple (3 or more) drugs compared to the no-problem behaviour control group who were only prescribed multiple psychotropic drugs at a 7% rate. A recent cross-sectional study from the Netherlands showed that the prevalence of antipsychotic drug use in 2373 individuals with ID living in the community was 32% (De Kuijper et al., 2010). The study examined
pharmacy records to determine the prevalence of psychotropic medication use in this population (De Kuijper et al., 2010). They found that the main rationale for drug prescriptions were behavioural problems, in 58% of cases, and secondly, for a psychotic disorders or symptom in 5% of cases.

In a 2004 Norwegian study, researchers looked at the prevalence of psychotropic medication use in 300 people with ID living in the community (Holden & Gitlesen, 2004). Their results showed that 37% of the individuals used psychotropic medications. They also found that 26% of individuals used one medication, 9% used two, and 2% used three medications. Neuroleptics (also referred to as antipsychotics) were identified to be the most frequently prescribed psychotropic medications, then antidepressants, and then anticonvulsants. The most common rationales identified for the medications prescribed in their study were aggression, self-injury, destruction of property, and non-compliance. Only half of the psychotropic prescriptions in this Norwegian sample were indicated by a psychiatric diagnosis.

In a published Australian study, researchers examined the changes in psychotropic drug use across time by comparing a sample from 1993 to 2000 (McGillivay & McCabe, 2006). Their study examined the prevalence and types of psychotropic drugs used to manage behaviours. The results showed a decrease in antipsychotic use and increase in anti-convulsant and antidepressant use from 1993 to 2000. The results of the 2000 sample of 873 individuals who were identified as “chemically restrained” (p.165) found that, 83% were prescribed antipsychotics; 18.% anti-anxiety; 16% anticonvulsant; 21% anti-depressants (McGillivay & McCabe, 2006). Furthermore, the number of drugs received per individual increased from 1993 to 2000, 1.39 to 1.54 respectively. The rates of polypharmacy in both samples ranged from 29% to 38%
This study highlights the widespread polypharmacy within these samples and across time.

The main findings of the above studies in North America, Australia, and Europe revealed that the general prevalence of psychotropic medication use in people with ID ranges from 16 to 83%. There is still limited information looking at the conditions under which psychotropic medications are prescribed, the rationales for use, and regarding the evaluation and outcome monitoring practices. The aforementioned studies have provided some insight into the patterns of psychotropic drug use in community samples of persons with ID, however, most of the studies utilized different data collection methods, which may account for the range in rates. The ranges in prevalence of use may also reflect different standards or routines practices across countries and samples.

**Consensus Guidelines for the Use of Psychotropic Medications**

Guidelines have been developed to assist physicians or other health care professionals to better understand the behavioural issues and to help with treatment planning (Sullivan et al., 2006). A recent update to the 2006 Primary Care of Adults with Developmental Disabilities: Canadian Consensus Guidelines (Sullivan, Berg, Bradley, Cheetham, et al., in press) regarding behavioural and mental health, rejects the routine use of antipsychotic medications for problem behaviours (specifically, aggressive challenging behaviour) without a confirmed robust diagnosis of schizophrenia or other psychotic disorder. Guidelines from the University of Birmingham in the United Kingdom recommend that psychotropic medication only be prescribed if: a) based on sound empirical evidence; b) after considering and addressing consent issues; c) ensuring a functional assessment is completed if possible before using psychotropic medications for
psychiatric or behavioural issues; d) objectively measuring treatment outcomes; e) ensuring careful monitoring for potential side effects of treatment; f) conducting frequent and thorough reviews of progress with colleagues; and g) that they use the lowest optimal dose of medication possible (Deb, 2006).

Treatment guidelines for the use of psychopharmacology for individual with co-morbid intellectual disabilities, mental health, or behavioural issues must continue to be updated and disseminated to physicians and other clinicians on an ongoing basis to increase the provision of the most effective evidence-based treatments. There is a pressing need for medical professionals to adequately consider all the risks, as well as, potential benefits of pharmacological interventions prior to prescribing to persons with ID. A national survey of psychotropic drug use for the management of problem behaviours revealed that in 2010 in Canada there were no mandated policies or guidelines on use of psychotropic medication for the management of problem behaviours either provincially or nationally (Bradley & Cheetham, 2010). Furthermore, it is not a prerequisite for physicians who are prescribing psychotropic medications to individuals with ID to have training or experience working with this vulnerable group (Bradley & Cheetham, 2010). Despite being published in 2006, the guidelines recommended by Sullivan et al, are not mandated.

Summary

Research has shown that individuals with intellectual disabilities (ID) are at an increased risk to develop both mental health issues and behavioural problems across the lifespan (Sturmey, Lindsay, Didden, 2007). Studies from North America and Europe have shown that rates of psychotropic medication use in people with ID has remained high, 16 to 83% during the past two
decades (Aman, Sarphare, Burrow, 1995; Burd, Williams, Klug, Fjelstad, et al., 1997; De Kuijper et al., 2010; Holden & Gitlesen, 2004; Lott, McGregor, Engelman, Touchette et al., 2004; McGillivay & McCabe, 2006; Spreat, Conroy, Fullerton, & Bodfish, 2004; Stolker et al., 2002; van Schrojenstein Lantman-de Valk et al., 1995). Furthermore, psychotropic medications are most frequently prescribed to control problem behaviours without the actual presence or a diagnosis of a mental illness in individuals with ID (Bouras, 1999; Grey & Hastings, 2005; Haw & Stubbs, 2005; Matson, Bamburg, Mayville, et al., 2000; Matson & Neal, 2009). Many researchers examining the use of psychotropic medications for the management of problem behaviours report that the current literature includes many studies that are methodologically flawed and thus limiting the quality of evidence (Deb et al., 2007; La Malfa, et al., 2006; Matson et al., 2000; Matson et al., 2003; Matson & Neal, 2009). Currently, no studies have comprehensively examined and reported on factors such as, individual characteristics, patterns of psychotropic usage over time, the presence or absence of behavioural problems and behaviour plans, rationales for different drug use, most common poly-prescribing combinations, or characteristics of PRN usage, within the same sample of individuals with ID. This study has attempted to address the current research and literature gaps by examining the psychotropic medication use in an Ontario based Canadian sample of individuals with ID.

Research Questions and Hypotheses

The purpose of this study was to examine changes and patterns of psychotropic medication use over a one-year period for a group of 73 adults with a primary diagnosis of ID living in the community. This study brought together current information on prevalence and prescribing patterns, with current prescribing guidelines/standards regarding the use of
This study was designed to answer the following questions:

1. What are the characteristics of people who are taking psychotropic medications?
2. What are the rates and patterns of psychotropic medication use?
3. What are the documented reasons that psychotropic medications are prescribed?
4. Does psychotropic medication use for this sample of individuals living in community residential settings adhere to the guidelines recommended in the 'Consensus guidelines for primary health care of adults with developmental disabilities' (CME, 2006)
5. What are the relationships between client characteristics and psychotropic medication use for behavioural or mental health issues (not seizures), in persons living in community residential settings?

Method

Research Design

This study is a retrospective, longitudinal cohort study on psychotropic medication use over a year period in a sample of individuals with ID living in a community residential setting.

Participants

The sample consisted of individuals residing in residential group homes operated by a community agency. This agency provides residential housing and day programs to approximately 75 individuals, ranging in age from 21 to 68 years, with varying degrees and types of ID living in the Durham Region of Ontario, Canada. Database information was available for 76 individuals; however, only individuals living within the agency group homes during the entire period from February 2009 to February 2010 were included in the study. Three individuals were
excluded from the original $n$ of 76. Of these, one passed away during the course of the year
being examined, and two were newly admitted part way through the year. Data for 73
participants were included in the analyses. Informed consent was obtained from the participants
as a part of their service agreement with the agency when they first entered care. Consent was
obtained from the participants or their substitute decision makers for the collection of data to
permit the agency to complete program evaluation and to investigate aspects of care for service
improvement purposes. The data that were provided for this project was anonymous, and
adhered to individual client consent and privacy issues as indicated in the Freedom of
Information and Protection of Privacy Act (FIPPA), R.S.O. 1990, CHAPTER F.31, s. 21 (1) & s.
41 (1). The study was consistent with the program evaluation efforts of the' Community Living'
agency and the results will provide information to continuously improve the quality of services.
Permission for this study was granted from the Brock University Research Ethics Board for the
secondary analysis of these data.

Data Collection

The data were collected from a database maintained by a community living agency for
the purposes of: tracking medication, client treatment information and to enable monitoring for
quality control purposes. These data included: individual demographics, incidents reports,
medication errors, prescribed medications, medical/psychiatric diagnoses, treatment strategies;
and to provide monthly information for managers to be able to review and supervise their
residential programs. The primary student investigator assisted in the design, maintenance,
analysis and interpretation of the database as part of her job as a Behaviour Consultant prior to
the start of this study. Medication information included: name of medication, dose, route of
administration, and rationale for use, start date, date of recent medication review (past or future) for general health and psychotropic medications. Individual characteristics included: primary and secondary diagnoses, presence or absence of problem behaviour (may have one or more of: verbal aggression, physical aggression, self-injury, sexuality inappropriate, property destruction), presence of formal behaviour plans, rated intensity of support (based on Accreditation Ontario Classifications (minimal, limited, intermittent, intensive, extensive), individual monthly rates of incidents or ‘pro re nata’ (PRN) medication use. The database included additional information (i.e. medication errors, incident reports) however these data were not relevant to the research questions of this study.

Group home managers provided and updated the information about client profiles and treatment plans, contained within the database, to the information data coordinator, on a monthly basis. Individual medication information was documented on medication information sheets, which were provided by the pharmacy to the group homes, and then forwarded to the information data coordinator on a monthly basis. The accuracy of data provided by the managers was not checked routinely, unless obvious discrepancies were noticed. To ensure anonymity of participants, the information contained in the database did not include any personal identifiers, and was coded using numbers. Personal identifiers were not revealed or disclosed at any point during the study. The community living agency provided the student investigator with the excel database spreadsheets without identifying information.
**Procedure**

1. REB clearance was obtained for the secondary use of the data

2. Data were coded according to the medication categories: 1) general health, 2) all psychotropic medications.

3. The medications were then coded according to their rationale for use and drug classification (NIMH, 2008).
   
   a. The rationales included: anxiety, mood, psychiatric disorder, seizure control, behaviour control/no-psychiatric diagnosis.

   b. The medication classifications were as follows: first generation anti-psychotics (i.e. haloperidol, methotrimeprazine, perphenazine); second generation anti-psychotics (i.e., risperidone, quetiapine, olanzapine); antidepressants (i.e., fluoxetine, sertraline, bupropion, desyrel (Trazodone), mirtazapine, escitalopram, citalopram, venlafaxine, imipramine, fluvoxamine, paroxetine); anti-anxiety medications (i.e. lorazepam, clonazepam, diazepam, alprazolam, oxazepam); anti-convulsants/mood stabilizers (i.e., carbamazepine, divalproex sodium, valproic acid, clobazam, dilantin, lithium carbonate, lamotrigine, gabapentin, zarontin, primidone, benzotropine (for seizures), oxecarbazepine, nitrazepam, levetiracetam); hypnotics (i.e., zopiclone); and stimulants (i.e., methylphenidate) (NIMH, 2008).

5. The duration of use of each psychotropic drug was determined in excel using the start date: The duration categories were as follows: 0-6 months, 6-12 months, 1-5 years, 5-10 years, or >10 years.

6. Individual participant totals for February 2009 were imported into PASW for further analysis.

Statistical Analysis

Statistical analyses were completed using PASW version 18.0 and some descriptive analyses were completed using Excel 2007. PASW was used to calculate descriptive statistics: frequencies, sums, means, standard deviations, variance, distribution $SD$, skewness or kurtosis, and range. PASW was used to explore relationships between participant characteristics and the number of prescribed psychotropic medications. Continuous variables were correlated using Pearson’s Correlation Coefficient $r$. Nominal variables were correlated using Phi. Where continuous variables were correlated with nominal variables, point-biserial correlations were completed in PASW using Pearson’s $r$ (Field, 2009; Thompson, 2006) as there is no mathematical difference and the results would be identical (DeCoster, 2004).

Results

Characteristics of Sample Population

The sample included 73 participants, described in Table 1 below. The majority of people in the sample had no known etiology for their ID. Thirty-one individuals were identified as having seizures, although only 14 individuals had a formal diagnosis of Epilepsy.
Table 1

Demographic and clinical characteristics of the study participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Participants (n=73)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Frequency</td>
<td>Percentage</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>43</td>
<td>59</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>30</td>
<td>41</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>$M = 45.9$</td>
<td>(SD 10.4)</td>
<td></td>
</tr>
<tr>
<td>Primary Diagnoses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ID Unknown Etiology</td>
<td>56</td>
<td>77</td>
<td></td>
</tr>
<tr>
<td>ID Known Etiology</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>7</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Down syndrome</td>
<td>8</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>7</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Secondary Diagnoses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seizures</td>
<td>31</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Psychiatric Diagnosis</td>
<td>12</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Problem Behaviours</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>44</td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>Support Level Needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minimal</td>
<td>11</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Intermittent</td>
<td>8</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Limited</td>
<td>6</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Intensive</td>
<td>22</td>
<td>30</td>
<td></td>
</tr>
<tr>
<td>Extensive</td>
<td>20</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>6</td>
<td>8</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Participant ages range from 21-68.

More than half the participants in this study were identified as having problem behaviours. The most prevalent problem behaviours were verbal and physical aggression, self-injury, and property destruction. The varieties of problem behaviours are presented below in Figure 1. Some individuals have more than one identified problem behaviours.
Rates and Duration of Psychotropic Drug Use

The first available month of data (February 2009) was used to determine rates of psychotropic medication use. In the study sample of 73 participants, 61 participants (83.6%) were prescribed psychotropic medications (including seizure medications) and 54 (74%) were prescribed two or more psychotropic medications (polypharmacy; Deb, 2006). From this group of 61, 41 individuals (67%) had identified problem behaviours. There were 31 participants (43%) who were prescribed medications for seizure control, of whom only 14 had formal diagnoses of Epilepsy. Individuals in the ‘psychotropic medication group’ were prescribed a mean of 3.5 each, \( SD \ 1.69 \), with a range from 1-7 medications. There were 12 participants (16%) who had no psychotropic medications. General health medications were prescribed to 71 participants (97%). Seizure management medications comprised 30% percent of all psychotropic medications prescribed.
Almost 50% of the sample had been taking psychotropic medications from 1 to 5 years, and 42% for more than 6 years, see Table 2. No prescriptions were recorded to have been prescribed for longer than 10 years. The use of psychotropic medication by different subgroups is depicted in Table 2.

Table 2

Subgroups Taking Psychotropic Medications as a Percentage of the Sample

<table>
<thead>
<tr>
<th>Subgroups</th>
<th>Psychotropic</th>
<th>No psychotropic</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N ( %)</td>
<td>N ( %)</td>
<td>N ( %)</td>
</tr>
<tr>
<td>Participants</td>
<td>61 83.6</td>
<td>12 16.4</td>
<td>73 100</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>12 100</td>
<td>0 0.0</td>
<td>12 16.4</td>
</tr>
<tr>
<td>Seizure Disorder</td>
<td>31 100</td>
<td>0 0.0</td>
<td>31 42.5</td>
</tr>
<tr>
<td>Problem Behaviours</td>
<td>41 93.2</td>
<td>3 6.8</td>
<td>44 60.3</td>
</tr>
</tbody>
</table>

Note. Some participants’ belonged to more than one subgroup

Table 3

Duration of prescribed psychotropic medications within sample population,

<table>
<thead>
<tr>
<th>Duration of Use</th>
<th>Percent of Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-6 months</td>
<td>0.9</td>
</tr>
<tr>
<td>6-12 months</td>
<td>7.2</td>
</tr>
<tr>
<td>1-5 years</td>
<td>46.2</td>
</tr>
<tr>
<td>6-10 years</td>
<td>42.5</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Yearly Medication Changes

General health medications were found to increase over the 12-month period by 41 prescriptions across the whole sample, see Figure 2 below. Prescribed psychotropic medications per person fluctuated very little over the one-year period, see Figure 3. The most changes across
the year took place within the anti-convulsant medication class. The total psychotropic prescriptions decreased by one prescription over the full year period.

![Graph showing changes in the total number of prescribed medications across the sample from Feb 2009 to Feb 2010.](image)

**Figure 2.** Changes in the total number of prescribed medications across the sample from Feb 2009 to Feb 2010.

![Graph showing changes in the mean number of all psychotropic medications per individual from Feb 2009 to Feb 2010.](image)

**Figure 3.** Changes in the mean number of all psychotropic medications per individual from Feb 2009 to Feb 2010. Error bars represent standard errors.
Although there were few changes in the mean number of psychotropic medications per individual across the year, there were changes in dose (increase or decrease), and the start and stop of several medications for some individuals, see Figure 4. A total of 17 individuals had medication changes across the year period. These smaller scale changes were not evident when looking at total numbers of psychotropic medications.

![Medication Changes](image.png)

*Figure 4.* Yearly changes in the number of prescribed psychotropic medications.

**Medication Classes**

Over the year, the average rate of different medication classes prescribed psychotropic medications across quarters were: antipsychotics, 18.4%; anti-anxiety, 26.2%; antidepressants, 14.8%; anticonvulsants/mood stabilizers, 33.8%; hypnotics, 1.4%; stimulants, .5%; typical antipsychotics, 4.9% (see Figure 5). The most prevalent drug classes were anti-psychotics, anti-convulsants, and anti-anxiety medications.
Figure 5. Number of psychotropic medications prescribed from different classes over the year period.

Standard Daily Psychotropic Medications

The three most prevalent daily (standard) psychotropic medications prescribed were: Olanzapine, Risperidone, and Quetiapine as can be seen in Figure 6. The top three medications are all antipsychotics. The fourth most prevalence group of prescribed medications included: lorazepam, divalproex sodium, and citalopram. There were also several first-generation (typical) anti-psychotics still prescribed within this sample, they were: haloperidol, methotrimeprazine, and perphenazine. Methotrimeprazine was the 11th most prevalent medication, despite being an older generation antipsychotic, with a large side effect profile.
Figure 6. Profile of prescribed standard daily psychotropic medications. Medications prescribed only for seizure control and PRN medications are not included in this table.

PRN Medications

Within this sample of 73 participants, 24 individuals, 33%, were prescribed 'Pro re nata' (PRN) psychotropic medications, meaning prescribed as needed. The most prevalent PRN medication prescribed was, Lorazepam (Ativan), see Figure 7. A total of 31 individuals, (42%), from the entire sample, were prescribed Lorazepam as a PRN medication. A total of 14 individuals, 19%, were prescribed two or more psychotropic PRNs. The most prevalent combination of prescribed psychotropic PRN medications was Lorazepam and Quetiapine (Seroquel). See Table 4 for all Psychotropic PRN combinations.
Table 4

People prescribed more than one psychotropic PRN and the different combinations

<table>
<thead>
<tr>
<th>PRN Combinations</th>
<th>Individuals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lorazepam, Quetiapine</td>
<td>6</td>
</tr>
<tr>
<td>Lorazepam, Risperidone</td>
<td>1</td>
</tr>
<tr>
<td>Lorazepam, Methotrimeprazine</td>
<td>1</td>
</tr>
<tr>
<td>Lorazepam, Olanzapine</td>
<td>1</td>
</tr>
<tr>
<td>Zopiclone, Aprazolam</td>
<td>1</td>
</tr>
<tr>
<td>Quetiapine, Diazepam</td>
<td>1</td>
</tr>
<tr>
<td>Lorazepam, Haloperidol</td>
<td>1</td>
</tr>
<tr>
<td>Lorazepam, Oxazepam, Risperidone</td>
<td>1</td>
</tr>
<tr>
<td>Lorazepam, Quetiapine, Clonazepam, Zopiclone</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>14</td>
</tr>
</tbody>
</table>

**Figure 7.** Number of reported psychotropic medication prescriptions for PRN purposes.
The rationales and number of individuals who were actually administered (not just prescribed) PRNs, changed across the year, see Table 5. The most prevalent rational for PRN use was “anxiety”, followed by a medical reason (e.g. pain), self-injurious behaviour, and physical aggression.

Table 5

*Number of PRN administrations quarterly*

<table>
<thead>
<tr>
<th>PRN Rationale</th>
<th>Feb-09 (n = 26)</th>
<th>May-09 (n = 22)</th>
<th>Aug-09 (n = 17)</th>
<th>Nov-09 (n = 15)</th>
<th>Feb-10 (n = 16)</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal Assault</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Physical Aggression</td>
<td>28</td>
<td>17</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>48</td>
</tr>
<tr>
<td>Property Destruction</td>
<td>8</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Anxiety</td>
<td>9</td>
<td>20</td>
<td>36</td>
<td>32</td>
<td>42</td>
<td>139</td>
</tr>
<tr>
<td>Medical Appointments</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>12</td>
</tr>
<tr>
<td>Medical Reason</td>
<td>16</td>
<td>6</td>
<td>29</td>
<td>4</td>
<td>14</td>
<td>69</td>
</tr>
<tr>
<td>Self-Injurious Behaviours</td>
<td>12</td>
<td>29</td>
<td>16</td>
<td>0</td>
<td>0</td>
<td>57</td>
</tr>
<tr>
<td>Attempted Physical Assault</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Sleep Issues</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Obsessive Behaviour</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>87</strong></td>
<td><strong>77</strong></td>
<td><strong>87</strong></td>
<td><strong>45</strong></td>
<td><strong>68</strong></td>
<td><strong>364</strong></td>
</tr>
</tbody>
</table>

The rationales for PRN administration were grouped according to behavioural topographies. Destructive behaviour included PRNs administered to address: physical aggression towards others, self-injurious behaviour, and attempted physical assault. PRNs for anxiety were administered to participants experiencing anxiety that was visible, physical, or emotional. Other rationales included: verbal assault, medical appointments, obsessive behaviours, and sleep issues. Across the year the number of PRNs given for destructive behaviours decreased, and PRNs given for anxiety increased across the year, see Figure 7. The
overall quarterly rates of administered PRNs, decreased by 24%, across the year mainly due to the reduction in PRNs for destructive behaviour.

![Graph showing quarterly rates of psychotropic PRN use based on rationale.](image)

*Figure 8. Quarterly rates of psychotropic PRN use based on rationale.*

**Rationales for Psychotropic Medications**

The reasons for which psychotropic medications were prescribed are presented in Table 6. The most prevalent reason was identified as seizure control (with or without seizure disorder diagnosis), followed by anxiety and mood stabilization. Almost 11% of the medications were prescribed for problem behaviours, which included: aggression, agitation, behaviour unspecified, and self-injurious behaviour (see Table 6).
Table 6

Rationales for psychotropic medications (February 2009)

<table>
<thead>
<tr>
<th>Rationale</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizure control</td>
<td>26.0</td>
</tr>
<tr>
<td>Anxiety</td>
<td>21.6</td>
</tr>
<tr>
<td>Mood stabilizer</td>
<td>17.0</td>
</tr>
<tr>
<td>Psychotic symptoms</td>
<td>8.0</td>
</tr>
<tr>
<td>Depression</td>
<td>7.6</td>
</tr>
<tr>
<td>Aggression</td>
<td>5.2</td>
</tr>
<tr>
<td>Agitation</td>
<td>3.2</td>
</tr>
<tr>
<td>Bi polar</td>
<td>2.0</td>
</tr>
<tr>
<td>OCD</td>
<td>1.6</td>
</tr>
<tr>
<td>Tremors</td>
<td>1.6</td>
</tr>
<tr>
<td>Behaviour unspecified</td>
<td>1.2</td>
</tr>
<tr>
<td>Sleep</td>
<td>1.2</td>
</tr>
<tr>
<td>Self-injurious behaviour</td>
<td>1.2</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>0.8</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>0.8</td>
</tr>
<tr>
<td>Tourette’s symptoms</td>
<td>0.4</td>
</tr>
</tbody>
</table>

Note. Rationales are listed in order from most prevalent to least prevalent.

Relationships between Participant Characteristics and Psychotropic Medication Use

Pearson correlations were used to examine the relationships between the following variables: age; support level; number of problem behaviours; psychiatric diagnosis; behaviour plan; and number of prescribed psychotropic medications, see table 7. The primary relationships of interest, were variables that affected that number of psychotropic medications that were used for either behaviour control or mental health issues (not seizure control), therefore, medications prescribed for seizure control were excluded. Age showed a significant negative correlation with the number of problem behaviours. The number of problem behaviours was significantly correlated with the number of psychotropic medications and with the presence of a behaviour plan.
Table 7

Participant Characteristic Correlations

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.Age</td>
<td>.019</td>
<td>-.302**</td>
<td>.186</td>
<td>-.020</td>
<td>-.150</td>
<td></td>
</tr>
<tr>
<td>2.Support Level</td>
<td></td>
<td>.034</td>
<td>.012</td>
<td>-.044</td>
<td>-.141</td>
<td></td>
</tr>
<tr>
<td>3.Number Problem Behaviours</td>
<td></td>
<td></td>
<td>.098</td>
<td>.269*</td>
<td>.538*</td>
<td></td>
</tr>
<tr>
<td>4.Psychiatric Diagnosis</td>
<td></td>
<td></td>
<td></td>
<td>.000</td>
<td>.113</td>
<td></td>
</tr>
<tr>
<td>5.Number of Psychotropics</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.144</td>
<td></td>
</tr>
<tr>
<td>6.Behaviour Plan</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: Psychotropic medications did not include medications for the purpose of seizure management
** P < 0.01, two-tailed, * P < 0.05, two-tailed

Adherence to Standards of Practice

Canadian ‘Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities’ (Sullivan et al., 2006) recommends that medications are reviewed regularly (ideally every three months) with regards to (indication, dosage, efficacy, compliance, side effects); that dates and changes be monitored by the same health care provider; serum levels where applicable are tested regularly; and that psychiatric or behavioural pharmacological medications are reviewed at a minimum yearly basis to ensure appropriate or justified use for long term interventions. The data indicate that only 12.3% of the participants on psychotropic medications had a documented scheduled medication review within three months of the start month of this study. Individuals review dates for the remainder of the year period were not provided in these data. The documented rationales for receiving psychotropic medications did not correspond with reported numbers of psychiatric diagnoses. Excluding seizure medications, the majority of psychotropic medications, 77%, were prescribed to individuals with no documented psychiatric
diagnosis while 20.8% were prescribed for diagnosed psychiatric disorders. The rationale was unknown for 3 to 8 psychotropic medication prescriptions in different quarters. Only 48% of the participants with identified problem behaviours and no psychiatric diagnoses had an adjunct formal behaviour intervention.

**Discussion**

This study was designed to examine the prevalence and rationales for psychotropic drug use in a sample of 73 adults with ID living in community residential settings across a one-year period. This study provides new and more detailed information about the rationales for psychotropic medication use, prescribing practices, usage of PRN medications over time, types of medications changes over time, and whether psychotropic medications were reviewed within three months of the start of this study. Although the longitudinal data revealed that there were few medications changes over the year period (i.e. dose, new medications, stopped medications), information on the duration of use of psychotropic medications revealed that most individuals had been receiving psychotropic medications on a long-term basis and still rates of problem behaviours were high. The overall prevalence of psychotropic medication use and the use of polypharmacy in this sample was higher than expected based on previous prevalence studies from North America and Europe (Aman, Sarphare, Burrow, 1995; Burd, et al., 1997; Holden & Gitlesen, 2004; Lott et al., 2004; McGillivay & McCabe, 2006; Stolker et al., 2002). The examination of individual characteristics and variables and their relationships with psychotropic medication use revealed several significant relationships. The number of problem behaviours was found to significantly relate to the number of prescribed psychotropic medications, and the presence of a behaviour plan. Age was found to negatively correlate with the number of problem behaviours.
Patterns of Usage

Previous studies from North America and Europe showed that the prevalence of psychotropic medication use in people with ID ranged from 16% to 83% (Aman, Sarphare, Burrow, 1995; Burd et al., 1997; De Kuijper et al., 2010; Engelman et al., 2004; Holden & Gitlesen, 2004; Lott, McGregor, McGillivay & McCabe, 2006; Stolker et al., 2002; van Schrojenstein Lantman-de Valk et al., 1995). This results of this study revealed that 84% of participants in our sample were receiving psychotropic medications. The rates of psychotropic polypharmacy (2 or more medications per person) in this sample were higher than expected in that nearly 75% of the participants were taking two or more psychotropic medications. Prior studies showed that individuals with polypharmacy ranged between 7-62 % (Lott et al., 2004; McGillivay & McCabe, 2006). This present study found pervasive use of polypharmacy within this sample which is not consistent with emerging research and care guidelines warning against poly-prescribing of psychotropic medications for individuals with ID (Deb, et al., 2006; Deb et al., 2009; Kalachnik et al., 1995; Sullivan et al., 2006). The higher rates may have been related to the definition of polypharmacy used in this study. Studies on the prevalence of Epilepsy in individuals with ID have been found to range between 16-26% (McGrother, Baumik, Thorp, Hauk, 2006). Although only 14 individuals, 19%, had formally documented diagnosed seizure disorders in this sample, medications for seizure control were prescribed to 31 participants, (42%). This incongruence warrants further investigation. The number of prescribed seizure control medications was higher than expected. Additionally, more than half of the 31 individuals with seizures were prescribed two or more different psychotropic medications for seizure control. The high rates of medications for seizure control in this sample should be closely monitored and evaluated as seizure management with medication is typically long-term. The
high rates of psychotropic medications used within this sample, in combination with the long-term use of seizure medications, sets the stage for possible drug interactions, polypharmacy, and increases the likelihood of adverse side effects (Mahan et al., 2010; Matson et al., 2010).

This present study, replicated previous findings about the most common classifications of prescribed psychotropic medications (Holden & Gitlesen, 2004; Lott et al., 2004; Tsakanikos et al., 2007). The results showed that the most frequently prescribed classes for either mental health issues or behaviour control were anti-anxiety medications, antipsychotics, and to a lesser degree antidepressant medications. The most prevalence psychotropic class prescribed, irrespective of rationale, was the anti-convulsant class. This finding was not expected as only slightly less than half of the sample was reported to have had seizures. This may however be reflective of the increasing use of anti-convulsant medications for mood stabilization purposes (NIMB, 2008). The treatment of psychiatric disorders in individuals with ID using pharmacological interventions approved for the neurotypical mental health population is generally accepted (Deb, 2006). However, psychotropic drug use has stretched far beyond the treatment of psychiatric disorders in individuals with ID. An earlier Canadian study found that psychotropic medications were over-prescribed given the number of persons who had psychiatric diagnoses (Feldman, Atkinson, Foti-Gervais, & Condillac, 2004). Current results produced similar results and show that nearly 6 years later the number of people prescribed psychotropic medications still does not correspond with the number of diagnosed psychiatric disorders.

The current results also highlight other areas of concern: a) polypharmacy, b) the extensive long term of use of psychotropic medications, and c) the lack of documented regular medication reviews with physicians. Most individuals in this sample had been receiving psychotropic medication over long-term periods and research has shown that individuals with ID
are at greater risk of developing side effects because of their underlying neurological differences and possible neurological damage from long-term exposure to these medications (Mahan, et al., 2010; Matson et al., 2010). Despite this emerging information about the increased risk for adverse effects related to long term and polyphrescribing of psychotropic medications, the prevalence of long-term use and polypharmacy is evident in this sample (Allen, 2008; Deb et al., 2009; Haw & Stubbs, 2005; Mahan et al., 2010; Matson et al., 2010; Valdovinos et al., 2005). Furthermore, literature has shown that some side effects can actually lead to the development or increase in behavioural issues like agitation, aggression, disinhibition, hostility, restlessness, and sleep disturbances (Allen, 2008). Research has also shown that some side effects are reversible with the discontinuation of a medication, whereas some effects are permanent, and others can be life threatening (e.g. neuroleptic malignant syndrome) (Advokat et al., 2000). If side effects are not monitored more closely as a standard practice within this vulnerable population then psychotropic medications should not be used as commonly. What's more, general health medications are also often added to treat the side effects of psychotropic medications, thus increasing the number of prescribed medications and potential for drug interactions (Valdovinos, et al., 2005). The increase in prescribed general health medications during this study may be related to the management of emerging side effects from the long-term use of the psychotropic medications.

**Characteristics Related to Psychotropic Medication Use**

The variables related to psychotropic medication use were consistent with the existing body of literature. As was expected, there was a positive correlation between the number of problem behaviours and the number of prescribed psychotropic medications. Literature consistently
indicates that problem behaviours are predictors for the use of psychotropic medications in adults with ID (Aman, Sarphare & Burrows, 1995; de Kuijper et al, 2010; Holden & Gittlesem, 2004; Singh, Ellis & Wechsler, 1997; Tsakanikos, et al., 2007). More specifically, overt behaviours, such as, physical aggression, temper tantrums, pestering staff, self-injury, property destruction, verbal abuse, and over-activity, have been identified as risk factors for the use of psychotropic medications, despite the absence of any diagnosed psychiatric disorders (Tsakanikos et al., 2007). Studies across time and geographical regions have continued to find that problem behaviours are the rationales for that specific use of psychotropic medications, especially from the anti-psychotic classification (de Kuijper et al., 2010; Holden & Gittlesem, 2004; Stolker et al., 2002).

There was also a relationship identified between increasing age and a decrease in the number of problem behaviours. One possible explanation could be the decreased mobility and energy of individuals of older ages, resulting in a decrease in some overt problem behaviours. Furthermore, the changes in neurological functioning and extrapyramidal side effects resulting from long-term exposure to psychotropic medications may also affect an individual’s mobility and ability to engage in overt problem behaviours.

There was also a large discrepancy between the number of problem behaviours in the sample and the number of behaviour plans. This disparity may be partially explained by: a) variations in the severity of problem behaviours, where less severe behaviours may not prompt a referral to a behaviour support agency; b) behaviour plans may have been developed for individuals in the past, although they are no longer active; c) individuals may have been referred for behavioural supports and remain on a waiting list; d) support staff may be hesitant to make a
referral for behavioural support due to the response effort typically involved in the
implementation of behaviour support plans.

Standards of Practice

There have been several published guidelines regarding the best-practice
recommendations for the use of psychotropic medications with people with ID (Deb et al., 2006;
Deb et al., 2009; Sullivan et al., 2006). Previous studies have revealed a widespread lack of
commitment to following published guidelines on the use of psychotropic medications in
community settings (Cheetham & Bradley, 2010; de Kuijper et al., 2010; Holden & Gitlesen,
2004; Marshall, 2007). Similarly, in this present study, less than a quarter of the participants
who were taking psychotropic medications had a scheduled medication review within three
months of the start of the study. It is disturbing that individuals taking an average of 3 to 4
psychotropic medications each, were not scheduled a review at least every three months, since it
is understood that individuals with ID are more susceptible to negative side effects, increasing
with number of psychotropic medications prescribed (Mahan et al., 2010). Furthermore, the
rationales for prescribing the psychotropic medications did not correspond with actual numbers
of psychiatric diagnoses, but corresponded more closely the presence and number of problem
behaviours. Literature reports that agencies or caregivers will often turn to pharmacological
interventions as the first line treatment for treating maladaptive or challenging behaviours
(Matson, Mayville, Pinkston, et al., 2000).

Guidelines from Canada and Europe have made recommendations that psychotropic
medications not be used for convenience; in excess; or as a substitute for other psychological
services or if they appear to interfere with quality of life (Deb, Kwok, Bertelli, Salvador-Carula,
et al., 2009). Guidelines suggest that frequent drug changes, poly prescribing, high doses of medication, and the long-term use of benzodiazepines and anti-cholinergic medications be avoided (Deb, 2006; Deb, Kwok, Bertelli, Salvador-Carula, et al., 2009; Sullivan et al., 2006). This study demonstrates that further efforts are necessary to increase the implementation of the Standards of Practice and Health Care Guidelines in clinical practice.

Multidisciplinary Approach

Individuals with ID and mental health or behavioral issues have complex need and thus would benefit from a multidisciplinary and multimodal approach to the assessment and treatment of behavioural or mental health issues (Davis, Barnhill, Saeed, 2008). Literature indicates that treatment success can be improved through collaboration between medical and psychological/behavioural professionals, self-advocates, parents, and support staff (Dosen, 2007). Collaboration between professional would support current guidelines that clearly recommend a thorough assessment of biological, developmental, psychological, social, and environmental influences be conducted prior to the use of a pharmacological intervention for challenging or problem behaviour (Dosen, 2007). Furthermore, the implementation demands of various intervention techniques should also be considered in relation to an individual’s support network and their ability to effectively provide or support the most appropriate treatments (Fisher, Cea, Davidson, Adam, 2006).

It has also been recommended that the treatment planning process be recognized as a combined effort, whereas “the professionals carry the responsibility to communicate the plan using accessible format to the person with learning disabilities and their carers, the carers and patients have an equal responsibility to pass the right information to the professionals in the right
"way" (Deb, Sohanpal, Soni, Lenotre, 2007). Wachtel & Hagopian (2006) proposed a
‘neurobehavioral model’ towards assessment and treatment, which incorporates medical/
psychiatric and operant components in assessment, diagnosis, and treatment. Again the
application of this model would require the collaborative efforts of medical professionals and
psychologist or behaviour analysts in conducting accurate assessments and developing the best
possible treatments based on assessment results.

A multidisciplinary approach would help ensure that treatment strategies would address
any biomedical symptoms, aim to enhance quality of life for the individual with ID and their
caregivers, and focus on long-term positive changes (Deb, 2006). Furthermore, objective criteria
to indicate changes during an intervention should be clearly defined and then used to evaluate
treatment efficacy during any pharmacological intervention (Dosen, 2007). Basing treatments on
empirical evidence will help ensure the best possible outcome for an individual, reduce potential
for ethical misconduct within this population, and hopefully prevent ongoing use of strategies
that are causing a worsening of the problem or negative side effects.

**Study Strengths**

The present study had several strengths. This study examined a complex set of variables
and their involvement with the use of psychotropic medication over a full year. Although
previous studies have examined: prevalence, rationales, medication changes over time, predictors
for psychotropic medication use, no single study has combined and reported on all these
variables together (Aman, Sarphare, Burrow, 1995; Burd et al., 1997; De Kuijper et al, 2010;
Engelman et al., 2004; Holden & Gitlesen, 2004; Lott, McGregor, McGillivay & McCabe, 2006;
Singh, Ellis & Wechsler, 1997; Stolker et al., 2002; van Schrojenstein Lantman-de Valk et al.,
This study was the first Ontario-based study to comprehensively examine the prevalence and patterns of psychotropic medication use in adults with ID living in community residential settings. The database that was used for this study provided consistent information about individuals across time.

**Study Limitations**

The present study had several limitations. One limitation is that this study had a limited sample size of 73 individuals who were all supported by the same agency. Another limitation is that the investigator did not have access to diagnostic reports to confirm what was inputted into the database. Third, due to the aging population sample, there may have also been some missing diagnostic information due to the lack of genetic tools or stringent diagnostic criteria when individuals were initially diagnosed as children. Although the ‘level of support’ ratings reported for individuals in this sample were related to ‘level of functioning’ or ‘severity of ID’, there were no IQ scores or standardized assessment results available for participants. With regard to the recorded rationales for different medications, it is believed that some behavioural issues may have been described in psychiatric terms, such as, ‘agitation’ being reported as ‘anxiety’ as the reason prescribed. There was also no information about prescribing physicians’ expertise or specialty (i.e. psychiatry or family physician).

Data checks were completed on the drug categorizing by using the excel sort function to review specific drugs and their corresponding drug classifications before analyses were started. All data were taken from one master excel spreadsheet and totals or queries were cross-checked between excel and PASW. Totals were primarily calculated using descriptive statistics in PASW, a few using column totals calculated in excel. Although there may possibly be a small
margin of human error, it is unlikely that this margin would dramatically impact any of the results given the large number of medications in this sample.

**Future Research**

Future studies should examine the accuracy and variation of psychiatric diagnostic methodologies used with the population of individuals with ID currently living in community residential settings, to evaluate the current practices taking place. More thorough biopsychosocial assessments would be expected to assist in treatment planning and to ensure appropriate use of psychotropic medications for behaviour management purposes. It is important that future research also compare larger samples across different regions in Ontario and Canada to identify any differences in prescribing practices from urban and rural locations, as well as, the most common types of drugs prescribed by family practitioners vs. psychiatrists' vs. Emergency physicians. Future studies should carefully examine the main outcome effects and any side effects of psychopharmacological interventions for problem behaviours and psychiatric disorders in individuals with ID living in the community (Matson et al., 2000, Deb, 2007). There is also more research is needed which examines existing obstacles to the utilization of behavioral services. The methodological rigor of efficacy studies examining different medications for behaviour management purposes can be improved by: completing both functional assessments of behaviour and appropriate psychiatric assessments prior to treatment implementation; conducting randomized control trials; accurately monitoring and reporting adverse side effects; increasing the length of treatment or study periods; including longer follow ups; and providing objective measures to monitor (psychopharmacological or behavioural) treatment outcomes and side effects (Matson & Neal, 2009; Tyrer et al., 2008).
Because individuals with ID have been identified as more vulnerable to the adverse side effects of long-term use of psychotropic medications (Mahan et al., 2010; Matson, Fotstad, Neal, Dempsey et al., 2010), they would benefit from studies that investigated options about how to decrease the long-term use or misuse of psychotropic medications. Use of the ‘Consensus guidelines for primary health care of adults with developmental disabilities’ (CME, 2006) or the new Ontario quality assurance measures as explained in the ‘Services and Supports to Promote Social Inclusion of Persons with Developmental Disabilities Act 2008’, could be implemented as a medication reduction intervention. The existing barriers to the implementation of these guidelines could also be further investigated. Data from this present study could be used as the baseline, and future data as the changes measure. Research should also investigate the benefits or challenges in using a multidisciplinary biopsychosocial or neurobehavioural approach in treatment selection for individuals with ID (Griffiths, & Gardner, 2002; Wachtel & Hagopian, 2006). The biopsychosocial and neurobehavioural models would include biomedical assessments (including psychiatric assessment if needed) and functional assessments of behaviour prior to any medication and/or behavior plan administration and to account for any behavioural, social, or biological factors, which might contribute to problem behaviours or psychiatric illness (Deb et al., 2007; Griffiths, & Gardner, 2002; Wachtel & Hagopian, 2006).

Conclusions

Ideally, the use of psychotropic medications with individuals with ID for mental health issues or behaviour control would be based on the results of a thorough biopsychosocial assessment and empirical evidence of the proposed treatment efficacy. Some researchers suggest that the prevalent use of psychotropic medications is related to a reactive first-line response to
manage crises, (La Malfa, et al., 2006; Matson, 2007; Matson et al., 2000; Matson et al., 2000; Santosh, & Baird, 1999; Tsakanikos, Costello, Holt, et al., 2007). The use of psychotropic PRNs is also considered a relatively acceptable method of crisis intervention. There may also be increased reliance on PRN medication as some jurisdictions, including Ontario, limit or prohibit the use of physical restraint and other intrusive behavioural procedures (Jacobson, Foxx, Mulick, 2005). Nonetheless, as described throughout this paper, the efficacy claims of studies examining various pharmacological interventions for the purposes of behaviour management for persons with ID must be interpreted with caution and with an awareness of the existing methodological issues (Matson & Neal, 2009; Tyrer et al., 2008). Psychotropic medications for behaviour management purposes for individuals with ID should only be used when deemed appropriate following a thorough biopsychosocial assessment of the individual and possible causes of problem behaviours, and should be followed by the prescribing physician to ensure ongoing careful monitoring and rationale for any long-term uses.

Hopefully, over time there will be an increased willingness of the medical, psychological, and behavioural communities to collaborate in the treatment planning for mental health issues and behaviour problems in individuals with ID. This collaboration can be realized through dissemination of ongoing research in medical, behavioural, and psychological fields, increased public awareness about disability issues, and growing political pressures to provide lifelong ethical and effective treatment programs for individuals with ID. The integration of literature from medical, behavioral, and psychological research is essential in order to promote collaboration, rather than divergence in, treatment provision and future research directions. The regular dissemination of knowledge will help break down some of the existing barriers, such as,
a lack of discourse or communication across professions, to better enable most effective clinical practices and ethical treatment of individuals with ID living in the community.
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individuals with mental retardations: methodological issues and suggestions. *Research in
Developmental Disabilities,* 24, 149-157.


## Appendix A

<table>
<thead>
<tr>
<th>Medication Class</th>
<th>Main Neurological Effects</th>
<th>Reasons for Administration</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Antipsychotics:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Typical:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haloperidol, Thioridazine, chlorpromazine, perphenazine</td>
<td>Potent dopamine 2 receptor antagonism                                                   Psychiatric: schizophrenia, psychotic depression, mania, dementia</td>
<td></td>
</tr>
<tr>
<td>Dopamine (D2) receptor antagonism</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Atypical:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risperidone (Risperidal)</td>
<td>Dol-m-2 receptor and 5HT antagonism                                                      Behavioural: aggression, property destruction, agitation</td>
<td></td>
</tr>
<tr>
<td>Clozapine (Clozaril)</td>
<td>Dopamine (D2) receptor and 5HT antagonism                                                Behavioural: aggression, property destruction, agitation</td>
<td></td>
</tr>
<tr>
<td>Quetiapine (Seroquel)</td>
<td>Dopamine (D2) receptor and 5HT antagonism                                                Behavioural: aggression, property destruction, agitation</td>
<td></td>
</tr>
<tr>
<td>Olanzapine (Zyprexa)</td>
<td>Dopamine (D2) receptor and 5HT antagonism                                                Behavioural: aggression, property destruction, agitation</td>
<td></td>
</tr>
<tr>
<td><strong>Antidepressants</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selective Serotonin Reuptake Inhibitors (SSRI): Fluoxetine, Fluvoxamine, Sertraline, Paroxetine, Citalopram</td>
<td>Potent 5HT reuptake inhibition 5HT agonism, weak D2 reuptake inhibition</td>
<td>Psychiatric: Depression, panic disorder, obsessive-compulsive disorder, eating disorders and sleep disturbances.</td>
</tr>
<tr>
<td><strong>5HT agonist:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Buspirone</td>
<td>5HT agonism                                                                               Behavioural: self-injury, aggression, sleep problems</td>
<td></td>
</tr>
<tr>
<td><strong>Tricyclic antidepressants:</strong> Clomipramine, imipramine, Desipramine, amytryptiline</td>
<td>5HT reuptake inhibition, potent muscarinic2, histaminergic1, adrenergic2 antagonism        Behavioural: self-injury, aggression, sleep problems</td>
<td></td>
</tr>
<tr>
<td><strong>Mood Stabilizers &amp; Antiepileptics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lithium, Carbamazepine</td>
<td>Inhibition of inositol-1-phosphatase enzymeDecreases γ aminobutyric acid (GABA) activity Decreases GABA catabolism</td>
<td>Psychiatric: bipolar disorder</td>
</tr>
<tr>
<td>Valproate</td>
<td></td>
<td>Behavioural: aggression, sleep disturbances, agitation, irritability, self-injury, increased vocalizations, decreased attention span</td>
</tr>
<tr>
<td>Divaloprex</td>
<td></td>
<td>(Deb et al., 2008; Kern, 1999)</td>
</tr>
<tr>
<td><strong>Stimulants</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Methyphenidate</td>
<td>Releases dopamine and inhibits reuptake                                                  Psychiatric: attention deficit hyperactivity disorder (Deb, 2006)</td>
<td></td>
</tr>
<tr>
<td>Dexedrine</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anxiolytics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benzodiazepines (BDZ)</td>
<td>Increases GABA activity through agonism of BDZ receptor Enhances 5-HT activity           Psychiatric: anxiety disorders, panic disorder post-traumatic stress disorder</td>
<td></td>
</tr>
<tr>
<td>Diazepam, lorazepam, clonazepam</td>
<td></td>
<td>Behavioural: aggression, self-injury</td>
</tr>
<tr>
<td>Other: Buspirone</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other</strong></td>
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<tr>
<td>Opioid Antagonists</td>
<td>Blocks opioid receptors                                                                  Behavioural: self-injury (Kern, 1999)</td>
<td></td>
</tr>
<tr>
<td>Naltrexone</td>
<td></td>
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</tbody>
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