A Description of Psychotropic Medication Use in Institution and Community Settings in Ontario.

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_In the name of God, the Most Beneficent, the Most Merciful_ – it is common in the faith of Islam to commence something important with this statement. Thank you to my professor, Dr. Rosemary Condillac for providing guidance, encouragement and knowledge during this process. Thank you to my committee members: Dr. Barry Isaacs, Dr. Valerie Temple and Dr. Jane Summers for your feedback, support and wisdom. Melody Ashworth provided me with such a great friendship during this time. My family has provided so many provisions to help me excel, but specifically my passion for learning is modeled after my grandfather, Harry Misir, who is a true scholar and intellectual and who has studied for many, many years. Thank you to Yasmin and mom for your unconditional love. Uncle Rauf and Shashu you are both a great combination of intelligence and kindness. And last but not least, to my new husband, Rayshaud Jameer, thank you for your untiring support; you are my best friend.
Abstract

This study examined patterns of psychotropic medication use among 120 participants with intellectual disabilities (ID) who used to live in facilities and now reside in community-based settings in Ontario. There were significantly more participants taking psychotropic medication in the community (83.3%) than in the facility (74.2%). Of those who showed change, 4.2% were taking medication in the facility but not in the community, and 13.3% were taking medications in the community but not in the facility. While significantly more participants in the community were taking antipsychotic and antidepressant medications, there was no significant increase in psychiatric diagnoses after relocation. Additionally, PRN use was significantly reduced in the community while daily medication use was significantly higher. The most common PRN in both settings was lorazepam and the most common antipsychotics were risperidone, quetiapine and olanzapine.
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Introduction

Ontario has a long history of institutional care for people with intellectual disabilities (ID) dating back to the late 1800s. The deinstitutionalization movement began in Ontario in the late 1960s. The final wave of closures was announced in the fall of 2004. The last facility\(^1\) closed in April of 2009 (Lemay, 2009). Research into the outcomes of this process is vital to ensuring that it has lead to positive outcomes for persons with ID. The goal of deinstitutionalization is to allow people to be part of their communities and to enjoy an improved quality of life (Emerson & Hatton, 1996). Over 40 years of research have been conducted regarding the impact of deinstitutionalization in areas such as quality of life (Kozoma, Mansell & Beadle-Brown, 2009); health (Kozoma et al., 2009); mortality (Cooper & Picton, 2000); staff contact (Young et al. 1998), community participation (Cummings, 1990) parent involvement (Young et al. 1998), meaningful activity (Emerson & Hatton, 1996); and challenging behaviour (Golding, Emerson & Thornton, 2005).

However, few studies have looked at psychotropic medication use across and within psychotropic medication classes among individuals who have resided in an institution and thereafter transitioned into a community-based setting (Nottestad & Linaker, 2003; McGillivray & McCabe, 2005; Thinn, Clarke, & Corbett, 1990) including very little examination of Canadian samples (Gowdey, Zarfas & Phipps, 1987).

The purpose of this study is to closely examine patterns of psychotropic medication changes, that may be associated with relocation from an institution into a community setting in Canada.

\(^1\) For the purposes of this paper the word facilities and institutions will be used interchangeably.
Literature Review

**History of Deinstitutionalization**

During the 1920s – 1940s, individuals with ID were seen as inferior citizens who did not have rights and dignities (Wehmeyer & Patton, 2000). These notions propagated the amount of individuals referred to an institution setting. Large congregate settings (institutions) were built to segregate individuals who were born with an ID (Kugel & Wolfensberger, 1969). The development of institutions seemed to adequately solve this problem by housing individuals with ID who were seen as the 'disenfranchised of society' (Kugel & Wolfensberger, 1969). These institutions were built far from community settings; they were custodial instead of rehabilitative in nature and were primarily based upon a medical model of care. Since the 1960s, concerns have been raised about the standards of care (i.e., overcrowding, understaffing and underfinancing) for those living in these settings (Kugel & Wolfensberger, 1969). Kugel and Wolfensberger (1969) believed that to improve the standards of care, it was not only necessary to rectify these problems in the institution, but to also develop a community-based setting for individuals with ID, as integration was of paramount importance. The President’s Committee on Mental Retardation was commissioned, in the U.S. to review the condition of the institutionalized environment in 1967 (Kugel & Wolfensberger, 1969). The result of this review recommended a moved towards deinstitutionalization.

**Shift to Community Living**

In addition to the report commissioned by the President’s Committee On Mental Retardation there were similar movements happening in other parts of the world (Kugel & Wolfensberger, 1969), some of which had successful programs already implemented (i.e. Scandinavia) that challenged the notions about segregation. Positive changes started to occur in the legislature that
would lead to the provision of more support for individuals with ID (i.e. the Social Security Act, the Smith-Fess Act and the Fair Labor Standards Act) and by the 1960s – 1970s, talk of the unethical nature of the institutionalized environment became more prevalent. This, in conjunction with the concept of normalization, gave way to deinstitutionalization. Normalization refers to where “the mentally retarded should obtain an existence as close to normal as possible” (Kugel & Wolfensberger, 1969, p. 79) or “the utilization of culturally valued means in order to establish and/or maintain personal behaviors, experiences, and characteristics that are culturally normative or valued” (Wehmeyer & Paton, 2000, p.140). Hence, it emphasized that individuals with ID should be included and be able to live in a community-based environment, as opposed to, a segregated congregate setting outside of the community (Hamelin, Frijters, Griffiths, Condillac & Owen, 2011). An individual with ID also has the right to least restrictive environments, a choice in the matter of their personal care, access to loved ones and access to affordable housing. These concepts apply to all individuals regardless of their intellectual functioning. Advocating for these rights gave way to the development of community-based placements and a supported living environment (Hamelin et al., 2011).

In theory, the thought of community living encouraged individuals with ID to enjoy the same freedoms as individuals living in the community (Mansell, 2010). However, there was understandably much resistance from families regarding moving individuals with ID into a community setting. Some concerns reported in the literature (Tabatabainia, 2003) included a fear that the community placement may not support their relatives as well as an institutional environment would, possibly leading to regression of skills. There was a fear that the community placement would not provide a safe, sound, long-term place to reside in like the institution environment seemed to. There were concerns about staffing, mistrust of the government and trust in the
professional who initially lead them into thinking that the institutional environment was the best place for their children with ID to reside. For the deinstitutionalization process to be successful, it was necessary that the families of the transitioning individuals support the general deinstitutionalization movement (Tabatabainia, 2003). The initial negative perception that families displayed, helped shape the deinstitutionalization process by engaging the advocates of deinstitutionalization in answering some difficult questions about the overall procedure, namely, are outcomes in the community indeed better than in the institutional environment (Tabatabainia, 2003).

Setting up community placements appropriate for the diversity of individuals leaving the institutionalized setting proved to be difficult, as careful consideration is required for placement even for the individuals with less complex needs. For those with complex needs, it provided a challenge to the community to provide a placement suitable to their complexities (Mansell, 2010). Person-centered planning was a critical component to the deinstitutionalization planning and placement process. Person-centered planning consists of attention to the unique needs of the individual. Person-centered planning also looks to the individuals' strengths and inspirations as indicators for placements, as opposed to their risks or deficits. Secondly, and most important, this model seeks to utilize the individuals' family and support network as a resource. And lastly, it strives to achieve the goals set out by the individual, instead of working within the limitations of the system (Mansell & Beadle-Brown, 2004).

It is reported that individuals with less complexities were among the first to transition to the community, thereby leaving those with severe needs residing in the institution to transition last. Integrating individuals with severe needs (i.e. those with multiple diagnoses, physical disabilities and/or severe social impairments) back into community settings came with a variety of challenges.
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(Mansell, 2010). However, as mentioned above, research conducted has shown that there are positive benefits to living in community settings, regardless of the level of individualized need.

**Research Conducted on the Outcomes of Deinstitutionalization**

Researchers have been actively examining changes that have resulted from relocating from an institution to a community setting for people with ID. For example, extensive research has been conducted on adaptive behaviour outcomes (e.g., Hamelin et al., 2011; Joel & Betsy, 1983; Paul, Hall & Tameeka, 2005; Young, 2006) staff contact (Emerson & Hatton, 1996) and changes in challenging behaviour (Bhaumik et al., 2009; Golding, Emerson, & Thornton, 2005; Kim, Larson, & Lakin 2001; Kim et al., 2001). Research has also been conducted on making choices (Emerson & Hatton, 1996; Young & Ashman, 2004); engagement of meaningful activity and community participation (Emerson & Hatton, 1996; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002); contact with family and friends (Emerson & Hatton, 1996; Lamb, 1998; Molony, & Taplin, 1988); health, mortality and quality of life (Cooper & Picton 2000). Limited research has also been conducted regarding changes in medication use (Kozoma et al., 2009).

Generally speaking, results in most of the abovementioned areas have shown positive improvements regarding individuals resettling into community-based placements. Results regarding adaptive behaviour (personal competence) have generally shown positive improvements in individuals who have moved from institution-type settings to community-based settings. According to a review published in the UK during the 1990s which looked at 26 studies regarding adaptive behaviour (Emerson & Hatton, 1996), 67% of the research showed a positive improvement, while 33% showed no difference. However, only a few studies in their sample included longitudinal analyses. A plateau effect is seen in these select studies, with measures taken over a long duration of time where there is a significant increase in adaptive skills upon the move to the community but
then few additional gains are made after participants reside in the community setting over time.

Another study by Hamelin et al. (2011) reviewed 23 studies and reported that “moderate habilitative gains” were seen in 75% of the adaptive behaviour domains. Young (2006) also looked at adaptive behaviour across twelve and twenty-four months after relocation with a sample of individuals in the moderate and severe cognitive ranges. In this study he compared a community setting to a cluster setting and found that the community setting yielded higher results, but that adaptive behaviour improved for both.

Making choices is a necessary step in personal development and independence. Research consistently shows that a smaller, community-based setting is related to more opportunities for choice making and self-determination than large congregate settings (Kozma et al., 2009). Researchers emphasize that it is not the change of setting that guarantees outcomes but rather what occurs in that setting (Kozma et al., 2009). Young and Ashman (2004) conducted a repeated measures study in which all participants were followed for one, six, twelve, eighteen and twenty-four months during community living. Community placements were shown to increase the opportunities for choice making. Emerson and Hatton’s (1996) review of 12 studies found similar results although Young and Ashman (2004) noted that there is a difference between choice over daily decisions (which is high in community-based settings) versus choice over broader aspects of their lives. The latter of which is less available to individuals with ID.

Quality of life, also used to measure relocation outcomes, may refer to things like interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, rights, family, recreation, leisure, safety and security (Kozma et al., 2009). In most studies, relocation to the community has been associated with a better quality of life (Cooper & Picton, 2000; Kozoma et al., 2009; Young, 2004).
Community participation, meaningful engagement and relationships are another area of research commonly conducted during the deinstitutionalization era. The study of community participation and meaningful engagement is important because often large amounts of time pass where there are no activities, resulting in boredom, isolation and inactivity. This may also be attributed to improper planning by staff (Mansell et al., 2002). An Australian study found improvements in daily variation, normalized lifestyle and community interaction when looking at 85 young adults with severe mental retardation after four years of relocation (Cummings, 1990). A review of 13 Australian studies found an improvement in community participation and improved contact with family and friends (Young, Sigafoos, Suttie, Ashman, & Grevell, 1998). Another study found significant improvements in community participation and social-interpersonal relationships and that community participation was related to (a) goals set for the individual in care, (b) adaptive behaviour and (c) complexity of needs (Baker, 2007; Kozma et al., 2009). Also, family contacts tended to be re-established and maintained in the community-based settings over time (Kozma et al., 2009).

In respect to health and mortality, studies have shown that there may be little or no change with respects to individuals who have relocated (Young et al., 1998). While researchers have found that there is no evidence of trauma related to the transition of relocation, there do seem to be higher rates of mortality shortly after relocation. Looking into the ‘health’ of individuals with ID post relocations should take into account a variety of issues. For example, less restrictive living arrangements are associated with obesity, smoking and poor diet and community living opens up the possibilities of crime involvement and / or exposure to abuse (Kozma et al., 2009).

Staff interaction with individuals in community-based settings has received a lot of attention. For example, Emerson and Hatton (1996) reviewed 26 studies associated with staff contact and their
findings showed that the amount of time participants received contact from staff was 3-16% in hospitals but 5-31% in staffed houses. While the amount of time participants received contact from staff increased in staffed houses, it is still very low. Note that in the study by Emerson and Hatton (1996) they do not include ‘staff engagement’ as a part of ‘staff contact’. Staff engagement is a separate area. Staff engagement (time participants spend doing non-social activities and/or social interaction) is reported in a range between 2-23% for hospitals and 8-74% for staffed houses. The studies on staff interaction reviewed were published earlier (1980s-1990s) and it is likely many changes have occurred since then. More recent studies show, as well, that post relocation, staff contact increased and then increased again at a follow up time, when individuals were placed for at least nine months (Golding et al., 2005).

While research shows favourable findings when investigating the above-mentioned areas, there are more varied findings when looking at the decrease of aggression in community-based settings (Bhaumik et al. 2009; McGillivray & McCabe, 2005). It is reported that between 5 to 15% of adults with ID show challenging behaviours (Robertson, Emerson, Pinkeney, et al. 2005). Individuals that are characterized as having complex support needs may exhibit challenging behaviour, multiple diagnoses, comorbid psychiatric problems, possess physical disabilities, are non-verbal, and have limited capability to develop social relationships (Mansell, 2010; Robertson et al., 2004). These complexities require even more careful planning to find a highly suitable placement and therefore, attention needs to be given to this sub-population of individuals. Despite complex behaviour, there are supports available in the community that can be accessed and maintained to provide support to individuals with ID. A study conducted in the UK, which assessed challenging behaviour before and after relocation, has found that supports in community-based settings have led to a decrease in the observed occurrences of challenging behaviour (Golding et al.,
2005). Kim et al. (2001) conducted a review of behavioural outcomes of deinstitutionalization between 1980 and 1999. Their results show that ten longitudinal US studies found improvements in challenging behaviour after relocation, including a study reporting up to seventy-two months of results. In contrast, six studies (with two of these studies reporting on results at up to twenty-four months) reported increased levels of challenging behaviour (Kim et al., 2001). Other studies published in Norway also suggest an increase in challenging behavior shortly after deinstitutionalization (Nottestad & Linaker, 2001; Nottestad & Linaker, 2002). Golding et al. (2005) report that some studies show that no change is found when some individuals move settings. However, there may be a flaw in the method used to measure the occurrences of challenging behaviour because standardized rating scales tend to show no change whereas direct observation methods may be more sensitive to change. In many of the studies reviewed assessment tools, rather than direct observations, were used.

An area that is understudied in the literature is the use of psychotropic medication among individuals who have relocated as part of deinstitutionalization. For example, a systematic review conducted by Kozma et al. (2009) looked at 68 studies regarding outcomes in the different residential settings. The purpose of this study was to review findings that had emerged regarding deinstitutionalization. The 68 studies could be grouped into 10 categories: (1) community presence and participation, (2) social networks and friendships, (3) family contact, (4) self-determination and choice, (5) quality of life, (6) adaptive behaviour, (7) user and family views and satisfaction of family members, (8) health, risk factors and mortality, (9) challenging behaviour and (10) psychotropic medication. Out of these 68 studies, only 4 studies looked at the use of psychotropic medication and the results are inconclusive because some researchers have found a decrease in
medication use after relocation, some have found insignificant changes, and some have found an increase in medication use (Kozma et al., 2009).

**Psychotropic Medication**

Individuals with ID commonly exhibit behavioural disturbances (i.e. aggression, self-injurious behaviour, property destruction), and emotional and psychiatric disturbances that make them among the most medicated group (Bradley & Summers, 1999; Holder & Gitlesen, 2004). Even though psychotropic medication is employed as a treatment option, there is still much concern about its usage (Unwin & Deb, 2011). For example, the literature shows that psychotropic medication is effective in treating mental health diagnoses in individuals with ID, however, in some cases there are concerns about the efficacy of psychotropic agents used to treat challenging behaviour (Chapman, Gledhill, Jones, Burton & Soni, 2006), especially without a psychiatric diagnosis (Young & Hawkins, 2002). There is also evidence to suggest that individuals with ID are often over-medicated and undertreated (Bradley & Summers, 1999). Psychotropic medication may have severe side effects (e.g., tardive dyskinesia, weight gain etc.) and therefore should be prescribed with caution (Unwin & Deb, 2011). Individuals with ID are often given more than one medication for the same symptom (sometimes called polypharmacy) thereby exposing them to side effects from multiple drugs and a risk that drug interaction may be an additional long term negative effect (Mahan et al. 2010; Rinck, Guidry & Calkins, 1989). Studies such as the one conducted by Fodstad et al. (2010) aim to assess if the side-effects of the psychotropic medication truly outweigh its therapeutic benefits.

A large percentage of individuals with ID are prescribed psychotropic medications for the management of challenging behaviours (Matson & Neal, 2008). With the development of
institutions, many individuals who exhibited challenging behaviours were also commonly placed in an institution and therefore likely taking some sort of psychotropic medication (Mathson & Neal, 2008). As a result, the use of psychotropic medication in residential facilities has become a research focus (Briggs, 1989; Findholt & Emmett, 1990; Fischbacher, 1987; Fodstad et al., 2010; Poindexter, 1989; Robertson, Emerson, Gregory, et al. 2000; Silva, 1979). Research shows that up to 50% of individuals residing in institutions are taking psychotropic medications (Rinck et al., 1989).

Brandford (1996) reported that there was a prescribing prevalence of 23% of individuals living in Leicestershire (44% of those in the hospital, 19% in the community and 9% in families home). In Brandford (1997), it was suggested that antipsychotic medications were used for 30-50% of individuals living in institutions, 20-30% of those living in the community and 100% of those living at home with relatives.

With the closing of institutions, the responsibility of providing medical and social services became the responsibility of the community (Lannon & Vaughn, 2000). Therefore, studies have focused on truly assessing if community-based placements were in fact more beneficial than institutional environments. Studies have looked at medication use in community settings for individuals who have been relocated (Aman & Field & Bridgman, 1985; Bisconer, Sine & Zhang, 1996; Burd, et al. 1991; Gowdey, Zarfas & Phipps; Holden & Gitlesen, 2004; Martin & Agran, 1985; Zaharia & Struxness, 1991).

Studies have included participants from both an institution-type setting and a community-based setting (Clarke, Kelly, Thinn & Corbett, 2008; Harper & Wadsworth, 1993; Molyneux, Emerson & Caine, 1998; Robertson, Emerson, Gregory, Hatton, et al. 2000; Branford, 1997). These studies, however, have methodological limitations due to their use of a cross-sectional design (i.e. collecting data regarding medication use from participants living in different residential settings at
one point in time). Few studies have looked at psychotropic medication practices of individuals using a longitudinal design (i.e. looking at the same participants across time) (McGillivray & McCabe, 2005; Nottestad & Linaker, 2003; Thinn, Clarke, Corbett, 1990). Other studies have limitations in that they report on psychotropic medication use yet the focus of the study is really designed to look at challenging behaviour or psychiatric diagnoses and not psychotropic medication directly (Nottestad & Linaker 1999; Robertson, Emerson, Pinkney, Caesar, et al. 2005).

Medication use.

There is an ill-informed belief that psychotropic medication effective for those with a psychiatric diagnosis will be equally effective for those who have an ID (Holder & Gitlesen, 2004). Studies show that in fact, not all individuals with ID prescribed psychotropic medication even had a psychiatric diagnosis. For example, in Holder and Gitlesen (2004) only 54% of the population prescribed psychotropic medication had a psychiatric diagnosis and only 31.3% prescribed an antidepressant had depression. In the same study 53% percent of individuals were prescribed psychotropic medications due to a behavioural problem. These findings are corroborated by other researchers, such as Clarke, Kelly, Thinn, and Corbett (1990) who found that 83.7% of individuals with a psychiatric diagnosis were in fact receiving psychotropic medication. However, 36.2% of individuals without a recorded psychiatric diagnosis were also receiving medications. Other studies report that between 22% - 30% of individuals in an inpatient hospital received antipsychotics, where only about 4% of the population had a psychiatric diagnosis (Wressell et al., 2011). These studies show that there is a discrepancy between the number of individuals taking psychotropic medications and the number of individuals diagnosed with a psychiatric diagnosis.

A primary reason for this discrepancy is that many individuals with ID who are receiving psychotropic medications are receiving them as a way to treat challenging behaviours (Fleming,
Caine, Ahmed & Smith, 1996; McGillivray & McCabe, 2005; Robertson et al., 2000). Molyneux and colleagues (1998) suggest that antipsychotics (neuroleptics) are readily prescribed for the use of challenging behaviour. Chapman et al., (2006) report that more antipsychotics (36.7%) and antidepressants (23%) were prescribed to deal with behaviour than were prescribed for mental health reasons (antipsychotics 18.4% and antidepressants 19.2%). Fleming et al., (1996) indicate that reasons for the delivery of antipsychotic medications include behaviour problems, agitation, aggression, anxiety, verbal aggression, self-injurious behaviour, institutional behaviour, and schizoid-like outbursts. Bhaulnik et al., (2009) conducted a study of 51 participants all of whom had severe challenging behaviour. At baseline (six months prior to discharge), 67% of the participants were taking psychotropic drugs (for mental health and challenging behaviour). Post discharge, no changes were seen in the psychotropic drug use although 80% of participants' challenging behaviour improved. While this study shows that psychotropic medications can be effective, other researchers suggest that finding evidence to show the effectiveness of psychotropic medications when treating challenging behaviours is scarce (Oliver-Africano, Murphy & Tyrer, 2009; Tyrer et al. 2008), especially using randomized controlled trials. Tyrer et al. 2008 conducted a three-arm, parallel-group pragmatic trial of a placebo, haloperidol and risperidone with balanced randomisation but no stratification, into each arm. Their results showed that there was noted regression with all treatments after 4 weeks. The greatest decrease in aggression was in the placebo trial. There was no difference between groups regarding aberrant behaviour. Good evidence is lacking and inconsistent regarding antipsychotic medication use. Deb, Sohanpal, Soni, Lenotre and Unwin (2007) showed in their study, on the effectiveness of antipsychotic medication in managing problem behaviour, that there are two randomized controlled trial (RCT) studies. One with a sample
composed of adults and one with a sample composed of adults and children. These studies show that risperidone is effective but that there are risks such as adverse effects.

Psychotropic medications can pose significant risks when used inappropriately because of the many adverse side effects associated with their use (Clarke et al., 1990; Robertson et al., 2000). Wressell and colleagues (2011) report on a study by Aman (1984) that shows chlopromazine as having adverse effects on learning performance. In another study done by Chapman et al., (2006), 23% of individuals were prescribed antimuscarinics to reduce the Parkinsonian side effects of the anti-psychotic medication. Other negative side effects of medications include weight gain, irritability, learning inhibition and possible toxicity. Other common adverse reactions include anticholinergic effects (i.e. blurred vision, constipation, dry mouth, urinary hesitance), extrapyramidal symptoms (restlessness), sedative effects, tardive dyskinesia (i.e. involuntary repetitive body movements) and dermatological reactions (Wehmeyer & Patton, 2000).

When individuals are placed on medication it should be supervised by a consulting psychiatrist and reviewed by a multidisciplinary team. There should also be some effort to implement a behavioural-based program to decrease challenging behaviours as opposed to only changing or reviewing the medication when prompted by a significant change in behaviours or the appearance of side effects (Fleming et al., 1996). A more proactive approach needs to be implemented to assist in utilizing medications in a way that is helpful not harmful to individuals with ID. Therefore, ongoing research needs to look at current prescribing practices and their relationship to past prescribing practices to assess if there is indeed change. These prescribing practices were among the unethical practices identified in institutional environments. Rates of prescribed antipsychotic medication ranged between 25 - 50% of individuals living in an
Polypharmacy.

Polypharmacy occurs when more than one medication is prescribed, although some authors use it to reflect more than one medication being prescribed to treat the same symptom(s) (Holden & Gitlesen, 2004). Zaharia and Struxness (1991, p. 192) define polypharmacy as the use of “multiple drugs within the same class”. There is no agreed-upon definition of polypharmacy, but for the purposes of this thesis, studies that have included results regarding polypharmacy (regardless of the definition they have used) will be included in this review.

Polypharmacy has been shown to be of a concern in both community and institutional settings. Many studies also report on co-pharmacy (multiple drugs from different classes), however not much is known about the side effects of these combinations of different drugs. Individuals can receive multiple psychoactive agents (Harper & Wadsworth, 1993) and multiple neuroleptics agents but research cautions against this given that these agents are not synergistic in their action. Another example of common polypharmacy seen in the literature is the use of medications to deal with side effects of other medications (Branford, 1996). For example, anti-Parkinson drugs are prescribed to help the Parkinson-like side effects that result from the use of neuroleptics; this, however, is often discouraged because of its propensity to result in tardive dyskinesia.

Drug review programs.

Malpractice lawsuits began to develop in the United States due to the adverse side effects of psychotropic medication (i.e., development of tardive dyskinesia) and the inappropriate use of
medication. Some well known cases are Clites v. State of Iowa (1982); Faigenbaum v. Oakland Medical Center (1986); Hedin v. U.S.A (1985); Wyatt v. Stickney (1972); Garrity v. Gallen (1981); Wuori v. Zitnay (1978); and, Welsh v. Likings, (1976) (as cited in Rinck, Guidry & Calkins, 1989). These court cases collectively resulted in an increased responsibility to develop better standards for those caring for individuals with ID; hence, drug review programs were developed and implemented in numerous state facilities (Poindexter, 1989). These programs provided much insight into the prescribing practices of the medical community in relation to individuals with ID.

For example, a study by Branford (1996) looked at a drug review program in Leicestershire with participants from ward-type accommodations (47%), hostels (19%), group homes (14%) and private homes (21%). In this study, antipsychotics were among the most prescribed (thioridazine, chlorpromazine, zuclopenthixol and haloperidol), with antiepileptics, antidepressants, anxiolytics and hypnotics also being prescribed, but less frequently.

Briggs (1989) examined the long term effectiveness of an interdisciplinary drug review team in a residential setting for 697 individuals where monthly reviews were conducted and behavioural programs were implemented for challenging behaviour. Briggs (1989) found that psychotropic drug use remained at the low rate of 20%, a dose reduction for 91% of participants. The most often used medications were Haldol and Mellaril.

Rinck et al, (1989), in their study, looked at reviewing the States’ practices using psychotropic medication. The methodology of this study included an analysis of important variables such as the dose levels of each drug; rules regarding polypharmacy; the use of anti-Parkinson drugs that could lead to the development of tardive dyskinesia; drug interruption times (i.e. holidays) to evaluate the effects of the absence of medication; and, the use of a minimum effective dosage.
Results of this study show that there are more regulations for institutionalized settings than community-based settings (Rinck et al., 1989).

Research shows that an outcome of the implementation of drug review programs is the developed guidelines regarding prescribing practices when delivering medications to individuals with developmental disabilities; one such guideline being that psychotropic medication should not be used excessively, and should not be used as punishment or for staff convenience (Rinck et al., 1989). Psychotropic medication should be used as part of a multidisciplinary care approach within the context of a diagnostic and functional assessment. Specific behaviours should be tracked, side effects should be monitored and regular and systemic reviews should be implemented. Moreover, the lowest effective dose should be implemented first, with frequent drug and dose changes avoided. In regards to polypharmacy, the medication regime should be as simple as possible, and long term PRN usages should be avoided (Bisconer et al., 1996).

Lepler et al. (1993) conducted one of the first studies evaluating a psychotropic drug review process for individuals residing in a community placement. They found that utilizing an interdisciplinary team and a drug review program decreased psychotropic medication to a low rate of 17%, a reduction for 75% of participants. In this study, they also recommended using least intrusive measures first. Other studies found similar results in that these types of interdisciplinary teams and reviews are effective in reducing psychotropic medication use in institutionalized settings and in the community (Findhold & Emmett, 1990; Wressell et al., 1990).

In the 1980s, Michel and Kolakowska (see James, 1983) published guidelines regarding medication usage in response to concerns raised about the use of psychotropic medication in institutional settings. They recommended that polypharmacy be completely avoided, that long-acting drugs delivered on a frequent basis be avoided and that medication be reduced and or
discontinued if there was no evidence that it was indeed helping the patient (James, 1983). Thirty years later we are still facing these same issues when dealing with individuals with ID who exhibit challenging behavior in the community.

A study by Emerson et al. (2000) in a review of treatment procedures found that behavioural programming was used for 15% of individuals with challenging behaviour; sedation was used for 35%, physical restraint was used for 44% and seclusion was used for 20%. Also, Robertson et al. (2005) found that reactive management strategies were most often used in congregate settings. Following this, they found that physical intervention was most common.

Recently in Canada, *Tools for the Primary Care of People with Developmental Disabilities* (Developmental Disability Primary Care Initiative, 2011) have been published, with a specific section regarding psychotropic medication use recommending the following: (a) antipsychotic drugs no longer be used as routine treatment for challenging behaviours since other interventions are effective in treating behaviours; (b) attention be given to individuals on multiple medications due to potential adverse reactions; (c) there be a review of psychotropics every three months; (d) addressing behavioural crises and using medication as needed is permitted but this must be reviewed and explained to the caregivers; (e) medication doses should be started low and increased gradually; (f) individuals be monitored for side effects; and (g) a record be maintained of all prescriptions. There are also guidelines specific to the use of *Pro Re Nata* (PRNs), for example: (a) integrate PRNs into the overall treatment plan for the individual; (b) set a review time at the time of the PRN prescription and note why it was prescribed; (c) discontinue PRNs that have not been used for six months or longer; and (d) avoid prescribing more than one medication for any one symptom.
The few guidelines reported above have come from various countries during different time frames but they all allude to the same standard of care essential in ensuring the safety of the individual with ID.

Medication Use in Institution and Community Settings

Research has been conducted on the use of psychotropic medication in institutionalized environments since the 1960s. Studies conducted on deinstitutionalization are published from countries such as England, Canada, United States, Scotland, and Norway. It is reported that the rates of antipsychotic medication use in the institutions are as high as 40.2% (Clarke et al., 1990). Other reports show medication (antiepileptic and psychotropic) use as high as 50% (Harder, Kalachnik, Jensen & Felts, 1987). Research conducted in more recent years show similar results. For example, Robertson and colleagues (2000) showed that psychotropic medication rates in an institution ranged between 25% - 50%.

Some studies suggest that even though psychotropic medication use in the institution is reported to be very high, there is inconsistency in results when it comes to comparing residential and community-based settings. Some authors have indeed found that the institution environment is associated with higher rates of medication when compared to the community. For example, in the Robertson et al, (2000) study, psychotropic medication use in the community was reported to be 27% in community-based housing, whereas psychotropic medication use in the institution was reported at 56%. Those residing within private homes had a much lower rate of medication use at 17%. Branford (1997) reported statistics in that about 30 – 50% of individuals in institutions received psychotropic medication in comparison to 20 – 30% of individuals in the community and 10% of individuals living in private family homes. Other studies showed that rates in the
community and the institution remained the same (Emerson & Hatton, 1996; Nottestad & Linaker, 1999).

Currently, the literature presents a divided view regarding the use of psychotropic medications in the institution versus a community-based setting. Many studies have looked at psychotropic medication use in only an institutional environment (Briggs, 1989; Fischbacker, 1987; Poindexter, 1989; Rinck, Guidry & Calkins, 1989; Stone, Alvarez, Ellman, Home & White, 1989) and many studies have also only looked at psychotropic drug use in a community-based setting (Aman et al., 1985; Bisconer et al., 1996; Burd et al., 1991; Gowdey et al., 1987; Martin & Agran, 1985; Zaharia & Struxness, 1991). These studies were conducted in different countries during different time periods and used a diverse array of methodologies.

Medication Use in the Institution.

Stone et al. (1989) conducted a study of 6,450 individuals institutionalized with an ID. They found that medication use was divided into 6 classes (antipsychotics, antidepressants, anxiolytics, sedative / hypnotics, stimulants and other). They reported that in an institution located in California, 35.6% (range =13.7% - 63.6%) of their entire population of individuals with ID were taking psychotropic medications. The mean antipsychotic drug use was 26.8% (range = 11.0% - 59.6%) among participants residing in the institution. In comparison to other studies conducted, this was a wide range for medication use, as some reports were quite low in this regard. The authors report that these low rates may be a result of drug programs. Silva (1979) reported on a sample of 260 participants that 65.8% were prescribed at least one medication. The class of medications prescribed most frequently were major tranquilizers (Phenothiazines: i.e., mellaril or thiorisazine and haldol). The second most used medication class were anticonvulsants (i.e., dilantin, mysoline,
tirdione and zarontin). Individuals were also given phenobarbital but this was classified under a sedative/hypnotic which was the third most prescribed class. Minor tranquilizers (i.e., hydroxyzines, benzodiazepines and carbamates) were among the least prescribed. The authors included a fourth class of miscellaneous medications that reflected drugs such as antibacterial, analgesics, antibiotics, diuretics, hormones, laxatives, vaginals and vitamins, to name but a few.

Fischbacher (1987) reported on a residential setting for individuals with 'mental retardation' in Scotland and using a classification system similar to Stone et al, (1989). They reported on anticonvulsants, antipsychotics, antiparkinson drugs, emergency sedation, tranquilizers, antidepressants, replacement therapy, laxatives and contraceptives. A high percentage of their population exhibited seizures (182 out of a sample of 509) and as such, anticonvulsants were among the highest class of medications prescribed, including carbamazepine, phenytoin, sodium valproate, primidone and phenobarbitone. One third of the residents were taking antipsychotics (thioridazine and chlorpromazine) and two thirds were using haloperidol, droperidol and even lithium in a few cases. The authors reported that antidepressants were used infrequently because of the difficulty in recognizing depression in the ID population.

**Polypharmacy in the institution.**

Robertson et al, (2000) reported that in the residential setting, participants are more likely to receive antipsychotics and antidepressants than individuals in community or dispersed housing. In Branford (1997), two different time frames were compared and the results found were different to those in the Robertson et al, (2000) in that there was an increase in participants receiving antipsychotic and antiepileptic drugs. Branford (1997) noted that there were high rates of the prevalence of antipsychotics used in combinations with other psychotropic medication classes likely
attributed to physicians adding risperidone to the medication regime without stopping other medications. In Molyneux et al., (1998), nearly half the individuals were found to be receiving neuroleptics and antidepressants; this combination of medications being consistent with findings from Robertson et al., (2000). However, an American study by Briggs (1989) of a residential facility illustrated that the most consistent polypharmacy combination were antipsychotics and anxiolytics, and then, antipsychotics and lithium. An Australian study by McGillivray & McCabe (2005) with data from 1993 and 2000 revealed that in the year 2000, individuals were administered a mean of 1.7 drugs in the institution and 1.5 in the community, with those residing in the institution being more likely to receive three or more different drugs than those in the community. Alternatively, in the 1993 sample, polypharmacy was equal among community and institution-type settings. The percentage of individuals medicated across both time frames (recurrent sample) was more likely to receive more medications than those medicated across only one time frame.

Polypharmacy is affected by variables such as how long the individual was receiving medication and the nature of their challenging behaviours, as well as duration of time of symptoms (McGillivray & McCabe, 2005). The region in which the study was conducted may also have implications on polypharmacy; for example, in the United States, 21 states had regulations regarding the practice of polypharmacy for individuals in institutions, whereas there were no such regulations for individuals in the community (Rinck et al., 1989); hence this may have affected prescribing practices. Different studies showed different prevalence rates of different combinations of drug classes used but there are no clear and consistent findings. Polypharmacy is a necessary variable when studying medication use in individuals with ID because, as the research indicates, even in the most recent studies, it is still a concern.
**Medication use in the community.**

Studies have also looked at medication use in a community-based setting. Most studies were conducted using an adult population, with the exception of Aman et al. (1985), who included children in their sample. The majority of studies also used a questionnaire to gather information regarding medication. Common variables reported in studies conducted in a community-based setting were similar to those studies conducted in institutional settings, such as information on challenging behaviour, presence of a psychiatric diagnosis and/or the prevalence of polypharmacy.

Martin and Agran (1985) conducted a study including different variables than those previously mentioned. They looked at individuals in a community setting (apartments, single family home, psychiatric hospitals that provide short term service and or a nursing home). They collected data regarding the history of institutionalization, a variable not mentioned in many studies. Their results show that forty-nine percent of participants did not have a history of institutionalization. Alternatively, those with a history of institutionalization (70% of the 49%) were taking psychotropic and/or anticonvulsant medication at the time of the file review. By comparison, only 27% of those without a history of institutionalization used psychotropic medication. An interesting finding is that 64% of individuals without a history of institutionalization had received anticonvulsants in comparison to 41% who had been institutionalized. They also found that psychotropic and anticonvulsant medication use increased as individuals were living and/or working in restrictive settings. This study provides some evidence that psychotropic medication may be just as high in the community as in residential settings, as almost half the individuals in their sample were receiving medication. A limitation of this study is that they did not include information on polypharmacy.
Published studies tend to differ in their classification of psychotropic medication. For example, Burd et al. (1991) included classes such as propanalol, antihypertensives, lithium carbonate and hydroxyxine in addition to the classes mentioned in other studies (neuroleptics, antidepressants, antianxiety and anticonvulsants). This study also differed from previous ones in that they found anticonvulsant medications to be the most used drug group, higher than neuroleptics. However, Burd et al. (1991) found that psychoactive medication was only used by 37% of their sample, which was much lower than what Martin and Agran (1985) reported. Their participants were different in that Burd et al. (1991) looked at individuals in group home settings who were exposed to more restrictive work and living conditions than were presented in Martin and Agran (1985). However, both authors agree that these statistics are consistent with medication levels in an institutional environment.

An Ontario based study conducted by Gowdey et al. (1987) surveyed 1,389 residents looking at the names, doses and frequency of administration. Their results revealed that 40% of their sample received psychoactive drugs (23% anticonvulsants, 14% neuroleptics, 5% sedative / hypnotics, 3% antidepressants, 3% antiparkinsons and 1% antimanics). However, they did suggest that the frequency of prescribing anticonvulsant and neuroleptic medication was much less for community-based settings that those residing in institutions (Gowdey et al., 1987). Gowdey et al. (1987) has comparable rates of anticonvulsant use of 22.5% to that of Zaharia and Struxness (1991) who found anticonvulsant use at 21.8% in their sample.

Bisconer et al. (1996) reviewed psychotropic medication in a sample of 97 participants. Case managers, who completed a two-hour training, were assigned to give surveys to the participants. Drug classes used were consistent with previously cited studies. This study shows that 88.7% of participants were taking neuroleptics (in order of prescription, thiordazine [53
prescriptions], haloperidol, chlorpromazine, trifluoperazine, perphenazine, mesoridazine and thiothixene). The duration of time individuals were taking neuroleptics was between 2 months to 28.3 years. After neuroleptic use, there were 13 individuals taking antiparkinson medications for durations ranging from two months to thirteen (13.2%) years. Moreover, one individual was taking Phenobarbital (anxiolytic / hypnotic) continuously for fourteen years.

Studies conducted in the community-based setting indicated that medication use was still, in some cases, as high as in an institutional setting (Branford 1997). More studies are needed on comparing a community-based versus an institutional setting with participants transitioning from an institutional setting to a community-based setting. As Martin and Agran (1985) found, the history of the participant has an impact on the medication they receive. Therefore, an important variable in reviewing studies conducted is determining / looking at individuals with a history of institutionalization.

**Polypharmacy in the community.**

In a community-based study of 1,389 participants in Canada, Gowdey et al, (1987) found that one half of the residents received two or more psychoactive drugs a day. Also, 56% of individuals taking anticonvulsants were on two or more a day. Zaharia and Stuxness (1991) also showed in their community-based sample in Colorado that multiple psychotropic drugs were delivered within a class. Combinations reported in order of most utilized are 1) anti-convulsants + anti-psychotics; 2) anti-parkinsonian + anti-psychotic; 3) lithium + anti-psychotics; 4) anti-anxiety + anti-psychotic; 5) lithium + anti-convulsant; 6) anti-depressant + anti-convulsant; 7) anti-depressant + anti-anxiety; 8) anti-depressant + anti-parkinsonian; 9) lithium + anti-parkinsonian; and, 10) lithium + anti-anxiety. In another study conducted in a group home setting, Burd et al., (1991) did
not report on the specific combinations but reported that out of 809 participants, 37% were taking one or more medications; 12% were receiving two or more; and two residents were taking six different psychoactive medications while 49 individuals were reported to be taking medication from two different drug classes.

A Norwegian study by Holden and Gitlesen (2004) reported lower rates of polypharmacy than the North American studies. In a sample of 300 adults, only 27 (9.2%) were reported to be taking two medications and seven (2.4%) were reported to be taking three; the total prescriptions written per participant being 1.37.

Comparisons of Medication Use in Institution and Community Settings.

There are numerous studies comparing individuals living in the community with individuals living in an institution in order to better evaluate psychotropic medication use. These studies have been published in a wide array of countries (Branford, 1997; Harper & Wadsworth, 1993; Harper, Wadsworth & Michael, 1989; McGillivray & McCabe, 2005; Molyneux et al., 1998; Thinn, Clarke & Corbett, 1990; Nottestad & Linaker, 1999; and Robertson et al., 2005).

An English study published by Branford (1997) served as a follow-up study to an initial study conducted in 1990. In 1990 they surveyed 486 residents, 93% of whom lived in ward-type settings. Of these 486 participants, 44% were taking antipsychotic drugs, 44% were taking antiepileptics, 6% taking antidepressants, 13% taking anticholinergics, 3% taking anxiolytics and 5% taking hypnotics. In 1996, the authors were able to locate 394 of the original 486 participants. Of the 394 participants, 32% lived in ward type accommodations, 24% in health-care group homes, 13% in social-care homes and 31% in private homes. Results showed that in the 1996 sample, the prescription of antidepressants increased significantly. There was also an increase in the polypharmacy of antipsychotic and antiepileptic drugs. Branford (1997) suggested that
psychotropic medication in the community may be as equally high as psychotropic medication in
the institution because community settings are less likely to tolerate behaviours that were acceptable
in institutionalized settings. Even though there was little change in the overall frequency of
prescribing of medicines, the type of medicine prescribed for each patient was different in 1990
versus 1996. A limitation of this study is that during 1990 to 1996, Leicestershire residence in
England went through changes as a result of the deinstitutionalization era (i.e. the closing down of
residential-type accommodations and drug review programs). The results of this study should
therefore be understood within this context and should not necessarily be generalized to studies
conducted in countries that were not going through the same type of reformation.

Another English study conducted by Robertson et al., (2005) compared the nature and
prevalence of procedures used to treat challenging behaviour. Within the context of this study was
the use of psychotropic medication as a treatment choice. This study was part two of a study
conducted in 2002. Data was collected at two points in time, ten months apart, in two types of
settings. The first being a congregate setting where the majority of the participants had challenging
behavior and the second being a non-congregate setting where the minority of residents displayed
challenging behaviour. Robertson et al., (2005) used a longitudinal matched groups design on a
sample of 50 participants (25 participants from a congregate and 25 from a non-congregate setting).
A research analyst visited each client for 10 hours at time one (T1) and six hours at time two (T2).
At T2, more participants in the congregate setting were reported to receive more antipsychotic
medication (80%) in comparison to non-congregate settings (50%), but not at T1. Typical
antipsychotics were most often prescribed in both congregate (64%) and non-congregate (44%)
settings at both T1 and T2. The authors suggested that prescriptions did increase due to the recent
release of risperidone. Limitations of this study include the presentation of only correlational data
between methods of treatment and setting. Also, the duration of time between T1 and T2 was relatively short (i.e. 10 months). Participants in the congregate settings were reported to have more challenging behaviours than the participants in the non-congregate settings. This might explain higher rates of medication use.

Hemming, Lavender, and Pill (1981) and Thinn et al., (1990) reported on a study conducted by Hemming (1984) where 51 adults with ‘mental retardation’ transferred from a large institutional setting into a small unit setting, with 50 controls remaining in the institution. Prescriptions were studied at 5 different times (before transfer, intervals of four months, nine months, one year and two years after transfer). Results from Hemming’s 1981 and 1984 (see Thinn et al., 1990) studies show a significant increase in antipsychotic medication prescriptions for transferred residents 4 months after transfer and a significant increase in the use of sedatives 9 months and one year after transfer. This study brings up the important analysis of the effects of transitions on individuals with ID and medications necessary to help ease ‘anxiety’ during this time.

Thinn et al., (1990) conducted a study in England comparing psychotropic drug use before and after discharge from hospital to community. They examined case notes for 81 participants with ‘mental retardation’ (moderate to severe retardation, 36 of whom had a seizure disorder) who had moved from two hospitals into the community between 1983 -1987. All participants had been residents of the community for at least six months. Data was collected (retrospectively) by recording all drugs prescribed to a participant (a) two years before discharge; (b) on the date of their discharge; and (c) at the time of a survey. This study only dealt with psychotropic and antiepileptic medication. Results indicated that the average time spent by participants in the community was twenty five months. As for participants psychotropic medication use 37.5% were receiving antipsychotics two years before discharge, 39% at discharge and 39% after living in the community;
for antiepileptics, 30% two years before discharge, 33% at discharge and 33% at follow-up. According to this study, medication use did not change significantly when individuals moved from a residential setting into a community-based setting. Thinn et al, (1990) suggested using a longer period of observation time in future studies.

Harper et al. (1989) conducted a similar study with 87 participants. Most participants had moderate mental retardation whereas other studies published included participants with a wider cognitive range. Participants that were analyzed lived in 6 congregate settings and 18 group care environments. The only distinguishing factor reported between environments is that congregate environments included 15 or more persons living per facility and the group care environments included 4 to 15 per facility. Research was gathered by an interviewer collecting information (on problem behaviours and medication use) during a forty minute session with the participant, their file and a staff member who knew the individual for up to four months. Psychotropic medication or antiepileptic medications were given to 49% of the population. Of those receiving medications, 60% received them continuously for five years or longer. Medications used in order of highest to lowest were phenothiazines, butyrophenones, antidepressants, lithium carbonate and amitriptyline hydrochloride. The authors noted that individuals with more severe problem behaviours were more likely to be in congregate settings. This was a limitation of many studies conducted before deinstitutionalized has ceased. Studies may have shown skewed results because those with the most challenging behaviours (and therefore, likely on higher rates of medications) were either the last to leave or in some cases, placed back into an institutional placement after a community placement had failed. This study also concluded that there were higher rates of medication use among those older in age, as well as, those who had lived in an institution for a long period of time. Future research should focus on more controlled studies to identify issues beyond size and location. Nevertheless,
this study highlighted some relevant factors regarding psychotropic medication use such as (a) length of time in the institution; (b) age of participants; (c) severity of problem behaviours; (d) staff tolerance; (e) staff client ratio; and (f) philosophy of the attending physician.

Investigating the role of the physician has been shown to be important in other studies. Molyneux et al. (1999) conducted a study in a community setting in Norway looking at factors that predicted psychotropic medication use. One in five adults was prescribed a neuroleptic medication (chlorpromazine, haloperidol, zuclopenthixol & trifluperazine) and this was predicted with 85% accuracy if the participant had challenging behaviour, a mental health problem, resettled from a long-stay hospital and was under the review by a consulting psychiatrist. One in ten participants was also prescribed anti-depressants (amitriptyline, fluoxetine, paroxetine) and anxiolytics / hypnotics (diazepam, chloral hydrate, nitrazepam & temazepam). This study extended the literature because it was one of few studies looking at the variable of a General Practitioner (GP) who provided care to individuals who had an ID in primary health care settings. This study also noted that the percentage of adults receiving anti-depressants was higher than in other community-based samples. Holden and Gitlesen (2004) reported in their study of prescribing practices in adults with ‘mental retardation’ that at times there were both a GP and a psychiatrist involved. Both of whom sometimes prescribed different medications. Psychiatrists tended to prescribe second generation neuroleptics and GPs tended to prescribe more antidepressants.

McGillivray and McCabe (2005) examined the associations between changes in medication use across a seven year time frame and the type of residential facility. All participants were receiving medication for behavioural restraint. The study was conducted as a comparison of the years 1993 (762 participants) to 2000 (873 participants) and included children and adults as participants. Participants that appeared in both samples (recurrent sample, and non recurrent
samples) were 318. Data was collected by looking at all reported cases of chemical restraint received by the Intellectual Disability Review Panel (IDRP). Other information gathered included gender, age, type of residential facility, number and type of medications (clonazepam was classified as a sedative and lithium was included under anticonvulsants), as well as, PRN use. The percentage of individuals reported to be using 'chemical restraints' in the 2000 sample was similar across the community (21.1 %) and institution (22.5%). However, in the 1993 sample, those reported to be using 'chemical restraints' was higher in the institution (29.3%) versus the community sample (17%). In 2000, polypharmacy was higher in the institution sample but when looking at the total medication use the mean number of drugs delivered in 1993 was less than in the 2000 sample. A number of factors could have accounted for the results seen in the year 2000. For example, individuals may have been taking medications since 1993 and therefore taking more medications by the year 2000. The most frequent drug type to be administered was antipsychotics in the 2000 (institution) and 1993 (institution and community) samples. Psychostimulants were also more likely to be given to participants in respite care. In the 2000 sample they were more likely to be given antianxiety/sedative and anticonvulant/mood stabilizer drugs in comparison to the sample in 1993. Looking more specifically at the recurrent sample, 64.1% of this sample had lived in the institution. The recurrent sample also had higher rates of being administered more than one drug (35.3%) compared to 25.8% in the limited sample. In summary, there were no differences in the 2000 sample regarding the proportion of individuals receiving drugs. However, individuals in the institution did receive a greater number of medications concurrently than those in the community sample. In 1993, drug use was greater among those living in the institution than among those in the community. Yet, a limitation of this study was that participants in the community setting may have been individuals who were easily managed in a community placement and therefore placed there for
that reason. Alternatively, those in an institutional environment may have had higher rates of challenging behaviours and therefore, more likely taking medication. As such, future research should be conducted where this selection bias does not exist.

An English study by Clarke et al, (1990) compared the use of antiepileptic medications (during 1985-1987) in three residential settings. This study is important as it specifically reports that antiepileptic medication use is reported to be as equally high (between 20 - 45%) as psychotropic drug use. Information was gathered from the adult training center (these adults typically lived in the community, respite or family homes) and the mental handicap hospital. Specially trained informants collected information from participants through a questionnaire interview. No information was gathered about the drug doses and names. However, a record of whether the drug was a psychotropic or epileptic was obtained. Antiepileptic and psychotropic medications were shown to be higher in the institutions than in community placements. These findings are contrary to those of Thinn et al, (1990).

In summary, most studies conducted on medication use in a community versus a residential setting were carried out during the deinstitutionalization era. Studies by Thinn et al, (1990), Nottestad and Linaker (2003) and McGillivray & McCabe (2005) included an analysis of settings across three points in time with the same participants. Most other studies did not include a longitudinal analysis of psychotropic medication with a sample of participants that had relocated from the institution to a community setting. Many studies compared a sample of participants in an institution environment to a sample of participants in a community setting. There is a selection bias that exists with this type of method, as it is likely that a sample of those in institutions were residing in the institution due to their challenging behaviours and or multiple/psychiatric diagnoses. Both of which, have been shown to be positively correlated with higher rates of medication usage.
Future research should focus on studying psychotropic medication use within the context of post deinstitutionalization (relocation), where participants who now live in community-based settings will be compared to themselves when they used to reside in the institution.

Summary

The literature is inconsistent regarding the type of residence that has higher rates of medication use (i.e. the institution or the community-based setting). But, the literature is clear regarding low rates of medication use in private homes in comparison to community-based settings and institutions. Many studies suggest that psychotropic medication is the most often prescribed medication in both community and institution-type settings. Nonetheless, there are studies that show anticonvulsant and antiepileptic drugs are highly prescribed as well (Aman, Carolyn, Field & Bridgman, 1985). There are many important variables when studying medication use such as, the size of the setting and/or the restrictive nature of the setting, severity of the disability, challenging behaviours and prescribing practices (Martin & Agran, 1985).

Given all of these factors, it is necessary to continue to conduct research that allows us to systematically test these hypotheses. Also, the location of the study conducted may have implications on the findings. For example, studies conducted in the United States and England often tend to have drug review programs in operation that may or may not affect the results of the study. Even within the United States, different states have different regulations that affect their prescribing practices (Bisconer, Sine & Zhang, 1996). Research has been conducted in countries such as Norway, Scotland, Australia, United States, England and Canada, though very few studies have been conducted in Canada regarding psychotropic medication (Gowdey et al., 1987; Sokolowski, 2011). As such, more future research should be focused on Canada and its use of psychotropic medication.
A major limitation of the methodologies of the studies reviewed is the comparison of different individuals at one point in time who resided in two different settings (i.e. the institution and or the community-based setting), as opposed to, comparing the same individuals who resided in the institution to their relocation in the community (longitudinal design). When comparing the former, it is noted that individuals residing in the institution were likely there because they exhibited higher rates of challenging behaviour than those who had already transitioned (typically used as the comparison group). This dynamic likely skewed the results of studies. There is a lack of studies using the latter design. More studies need to be conducted with this type of methodology. Also, the time of data collection post relocation should be longer than six months as suggested by Thinn et al, (1990).

The purpose of this study is to extend the literature by conducting research on individuals with ID who have relocated from facilities to community settings in Canada. There have been no studies published in Canada on psychotropic medication use of individuals post the deinstitutionalization era. Therefore, this study aims to provide useful information that allows us to compare prescribing practices in Canada with those of other countries, as well as, to better the quality of lives of individuals with ID residing in Canada.

Future research should indeed definitely include more studies conducted in Canada, as very few of them have been done (Gowdey et al., 1987; Sokolowski, 2011) within the context of a Canadian deinstitutionalization setting.
Research Questions

The purpose of this study is to describe the patterns of usage of psychotropic medication among a population of 120 individuals with ID who lived in an institution and now reside in a community-based setting. Specifically, this study will address the following research questions.

1. What is the prevalence of psychotropic medication use for people who transitioned from the facilities to the community?
   a. How many people took psychotropic drugs in the facilities and in the community? This question will provide an analysis of four groups:
      I. Individuals who took psychotropic medication in the facility and community;
      II. Individuals who took medication in the facility but not in the community;
      III. Individuals who took medication in the community but not in the facility and
      IV. Those who were not taking psychotropic medication at all.
   b. Do the people in these groups differ with respect to their:
      I. Age, time out of facility,
      II. Adaptive behaviour (SIB-R),
      III. Problem behavior (BPI), and,
      IV. Mental Health (REISS)?

2. What types of medications were used in the facilities and communities, and did this change? If so how? This question will more specifically look at.
   a. Class
   b. Specific medications
   c. Number of psychotropic medications
   d. Combinations of medications, and,
3. Do the individuals taking psychotropic medications have:

   (a) Psychiatric diagnoses, and,

   (b) Access to mental health care?
Method

Research Design

This study is a longitudinal study on psychotropic medication use in among individuals with ID who are part of the deinstitutionalization process. Data has been collected in two points in time (T1= the last assessment in the facility and T2= the first assessment in the community). The data from this study was collected as part of a larger project: The Facilities Initiative project led by Dr. Rosemary Condillac and Dr. Dorothy Griffiths.

Participants

Participants were 120 adults ranging from 33 to 77 years of age with varying degrees of cognitive abilities recruited from the last three residential settings to close in Ontario. Letters of invitation were sent to a total of 975 participants with a ID, 120 of which are included in this study.

Data Collection

Consent to contact forms were sent to the family members and community support agencies of 943 former residents of facilities in Ontario by the Ministry of Community and Social Services. Project coordinators contacted potential participants via telephone to provide additional information regarding this part of the study. Those interested in participating, were sent specific letters of information and consent forms for the individual and for a staff participant. Once consent was obtained, a visit was booked for the research assistants (RAs) to visit their place of residence to collect data. During the visit, the RA sought assent from the individual with ID. If individuals displayed any behaviours that the RA and direct-care staff interpreted as a request to terminate the interview or observations, the RA would cease the interview. One participant requested to terminate the interview after the InterRAI ID was completed, though that participant asked to have her data retained for use.
Measures to Describe Sample

*Scales of independent behaviour-revised.* (SIB-R; Bruininks, Woodcock, Weatherman & Hill, 1996).

The Scales of Independent Behavior-Revised (SIB-R) is a norm referenced assessment that assesses 14 areas of adaptive functioning and 8 areas of problem behaviour. The 14 areas of adaptive functioning fall under the following five categories (1) motor skills; (2) social interaction; (3) communication skills; (4) personal living skills and; (5) community living skills. The SIB-R short form was delivered pre-assessment and took 15-20 minutes to deliver. The support score was used to calculate adaptive functioning, with a higher score meaning less help needed. For the purposes of this study, only the adaptive measures were computed and used in this study, as problem behaviour scores will be computed using a different measure.

Psychometric properties for the SIB-R show that mean split-half reliabilities for adaptive behaviour ranged from 0.88-0.98. Test-retest reliability coefficients ranged from 0.96-0.97.

*Behaviour problems inventory.* (BPI; Rojahn, 1984).

The BPI is a 52 item rating scale instrument for individuals with ID that assess problem behaviour. Items on the instrument include self-injurious behaviour; stereotypic, aggressive and destructive behaviours. All items are rated on a five-point frequency scale and on a three-point severity scale. The reliability and validity of this measure has been investigated. Test-retest reliability was poor for the stereotypy subscale but ranged from 0.67 to 0.7 for the other subscales. Internal consistency was found over most subscales ranging from 0.6-0.8. Lower internal consistency was found on the SIB subscale (0.4-0.48). Validity results indicate that the aggressive and destructive subscale had an r value of 0.55. Self injurious and stereotypic subscales scored r=0.21 and r=0.32 respectively (Rojahn, Matson, Lott, Esbensen & Smalls, 2001). For the purpose of
this study, the frequency scores of all sub measures are added together to create a problem behaviour score. A high score means more problem behaviours.

**The interRAI ID.** (*Martin, Hirdes, Fries & Smith, 2007)*.

The interRAI ID (Martin et al, 2007) is a 391 item scale spanning 20 domains. These domains are personal information, health service inquiry, cognition, communication, hearing and vision, physical functioning, self care, physical health medications, skin conditions, oral and nutritional status, psychiatric diagnoses, mental state indicators, life events, behaviour, psychosocial wellbeing and social supports, education, vocation, recreation, prevention, intervention and home environment. For the purposes of this study the physical health medication section will be used. The interRAI ID was created especially for persons with ID and has been used to aid in the planning process regarding deinstitutionalization. The interRAI ID has been shown to have good psychometric properties. The interRAI ID has been tested on 160 community-based residents, showing acceptable levels of internal consistency. Cronbach’s alpha ranged from 0.74 to 0.93. Majority of items exceeded standard cut-offs for acceptable reliability (Hirdes et al, 2008).

**REISS Screen for maladaptive behaviour.** (*Reiss, 1994)*.

The REISS is a 36 item tool across eight subscales that screens for mental health problems and psychiatric disorders in individuals with ID who are 12 years or older. The eight subscales include autism, psychosis, paranoia, depression (behavioural), depression (physical), dependant personality disorder and avoidant. A rater reviewed the 36 symptoms under these eight subscales and rated them as either no problem, a problem or a major problem. The REISS was filled out by a parent, a teacher or professional who worked with the individual and took 20 minutes to complete. Psychometric properties have been established for the REISS, which has shown the instrument is valid in screening certain psychopathology. Cronbach's alpha coefficient was .91 for
the total score and varied between .57 and .86 for the psychometric scales. Children and adolescents who had a dual diagnosis received total scores approximately amounting to 1 standard deviation higher than those who did not have a dual diagnosis (Reiss, Valenti-Hein, 1994).

Training.

Research assistants (RAs) hired for this study and were masters students and trained clinician in the field of ID. Research assistants were trained by the primary investigator and had an additional three days of training during which thorough explanations of all of the measures were taught.

Procedure

1. Potential participants and their direct-support staff were contacted after they had initially submitted a consent-for-contact form. The study was explained to them in simple language and they were asked if they were still interested in participating. No measures were delivered at this time.

2. Agencies and/or families of interested participants were contacted for follow-up. During this conversation the risks and benefits of the study were discussed. If they were interested, consent forms and letters of invitation were sent to them.

3. When consent was received, an appointment was scheduled, and a detailed information package to help them to prepare for the visit was sent, including three measures for them to complete in advance, the BPI, the SIB-R, and the REISS.

4. At the scheduled appointment, assent was sought from the participant with ID, if the substitute decision maker had provided consent. The RA collected the measures that had been completed by the direct-support staff. The RA answered any outstanding questions and ensured that all questions on the pre-visit measure were completed.
5. The RA completed the interRAI ID with assistance from the direct-support worker and the clinical file as necessary.

6. Other measures were completed for the full study, including interviews, direct observations, and file reviews.

7. After the visit, interRAI ID data was entered into a secure on-line database by the person who completed the interview.

8. All other measures were entered into the main study data base by trained research assistants who also scored, coded, and double checked all data entered.

9. A master file for this study was merged using SPSS from the two data sets, and merging variables were triple checked to ensure accuracy.

10. A medication classification system from the National Institute of Mental Health (NIMH, 2010) was used to classify all psychotropic medications into (a) first generation antipsychotics, (b) second generation antipsychotics, (c) antidepressants, (d) anti-anxiety, (e) mood stabilizers / anticonvulsants, (f) hypnotics and (g) stimulants. All medications within these classes were coded into SPSS using a numerical classification system. Medications were identified that were not found in the NIMH medication list. These medications were cross referenced with a Developmental Pediatrician and a Psychiatrist as to (a) If it was a psychotropic medication and (b) what class listed in the NIMH list should they belong to.

11. The medications entered into the interRAI ID were string variables that needed to be hand coded to facilitate analyses. All psychotropic medications from the final medication list were numbered, and these numbers were applied to all psychotropic medications that were listed on the interRAI ID by the student investigator.
12. A research assistant conducted inter rater reliability (IRR) ratings on 25% of the data coded and found 99% agreement.

13. Classifications of medications into classes were completed using algorithms created in SPSS to ensure accuracy.

14. All analyses and cross tabulation were conducted using SPSS 19.

**Analyses**

Research questions regarding psychotropic medication examined:

1. Class of medication with a table showing frequency of use for each class at T1 and T2. As well as a description of specific class changes for those who changed.

2. Specific drug use with a table of frequency of each type of medication T1 and T2 as well as a description of specific changes for those who changed.

3. Number of psychotropic medications, total, mean, and description of specific changes for those who changed.

4. Combinations of medications (prevalence of different combinations), frequency of different combinations T1 and T2 as well as descriptions of specific changes for those who changed.

5. PRN use, the number and types of PRN meds as well as the description of specific changes for those who changed.

All statistical analyses were performed using SPSS software and a significance (alpha) level of 0.05 was chosen for all analyzes.
Results

Characteristics of the Sample

Participants in this study were a total of 120 adults with ID (68 males and 52 females) who used to reside in facilities across Ontario. All participants are now living in community placements across Ontario. Each participant’s age was calculated using the first community visit assessment. The age range of the participants is from 33 years of age to 77 years of age, with a mean age of 54.8 years (see Table 1 below for entire sample demographics).

Table 1

Demographics Describing the Entire Sample

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>68</td>
<td>56.70</td>
</tr>
<tr>
<td>Women</td>
<td>52</td>
<td>43.30</td>
</tr>
<tr>
<td>SIBR Support Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intermittent</td>
<td>3</td>
<td>2.50</td>
</tr>
<tr>
<td>Limited</td>
<td>8</td>
<td>6.70</td>
</tr>
<tr>
<td>Frequent</td>
<td>32</td>
<td>26.70</td>
</tr>
<tr>
<td>Extensive</td>
<td>41</td>
<td>34.20</td>
</tr>
<tr>
<td>Pervasive</td>
<td>33</td>
<td>27.50</td>
</tr>
</tbody>
</table>

Note. The SIBR support level data is missing for three participants.

A summary of adaptive functioning as measured by SIB-R support levels (Table 1) shows that 3 participants (2.50%) required intermittent support (borderline deficits). Conversely, 41 participants (34.20%) required an extensive level (severe deficits) of support and 33 participants (27.50%) required pervasive support (profound deficits).

Challenging Behaviour and Mental Health

Table 2 shows participants’ BPI scores. The BPI instrument contains six subscales under three types of problem behaviours (SIB frequency and severity subscales, stereotypy frequency and
severity subscales, and aggressive / destructive frequency and severity subscales). All frequency scores are rated between 0-4 and all severity scores are rated between 0-3 (4= the most frequent, and 3= the most severe). Each problem behaviour scale has a different number of items. For example, the SIB subscale is rated on items 1-15. The highest possible score on the SIB frequency subscale is 60 and the highest possible score for severity subscale is 45. On the stereotyped subscale there are 25 items and on the aggressive / destructive subscale there are 12 items. In an effort to provide comparable scores, the total score per subscale was divided by the number of items in that scale providing a mean score per item that can be compared across scales.

Table 2

*BPI and REISS Scores for Participants in the Entire Sample*

<table>
<thead>
<tr>
<th>BPI subscales</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIB frequency scores</td>
<td>116</td>
<td>.00</td>
<td>1.4</td>
<td>0.31</td>
<td>0.32</td>
</tr>
<tr>
<td>SIB severity scores</td>
<td>114</td>
<td>.00</td>
<td>1.4</td>
<td>0.23</td>
<td>0.25</td>
</tr>
<tr>
<td>Stereotyped frequency scores</td>
<td>115</td>
<td>.00</td>
<td>3.3</td>
<td>0.74</td>
<td>0.71</td>
</tr>
<tr>
<td>Stereotyped severity scores</td>
<td>113</td>
<td>.00</td>
<td>2.2</td>
<td>0.46</td>
<td>0.46</td>
</tr>
<tr>
<td>Aggressive / destructive frequency scores</td>
<td>115</td>
<td>.00</td>
<td>1.8</td>
<td>0.25</td>
<td>0.34</td>
</tr>
<tr>
<td>Aggressive / destructive severity scores</td>
<td>115</td>
<td>.00</td>
<td>2.6</td>
<td>0.3</td>
<td>0.41</td>
</tr>
<tr>
<td>REISS total score (26 item)</td>
<td>116</td>
<td>.00</td>
<td>46</td>
<td>6.14</td>
<td>6.82</td>
</tr>
</tbody>
</table>

Based on descriptive statistics shown in Table 2, the highest mean scores are associated with both the stereotypy frequency and severity scores. Alternatively, low means were found in the SIB severity and frequency subscales.
Though there were many individuals in the sample taking psychotropic medication, few scored at or above the clinically significant range (cut-scores) on the Reiss (see Figure 1). As this measurement was taken while treatment was in progress, it is possible that the lower scores on this instrument indicate a positive treatment outcome.

![Figure 1](image)

*Figure 1.* Percentage of participants scoring at or above REISS cut-scores.

**Patterns of Psychotropic Medication Use**

Participants in our sample were classified into four groups. Group one consisted of those who used psychotropic medication in the facility and in the community. Group two consisted of those who did not use psychotropic medication in either setting. Group three consisted of those who used psychotropic medication in the facility but not in the community. Group four consisted of those who used psychotropic medication in the community but not in the facility. These groups are shown in Table 3. The majority of the participants (82.50%) belonged to groups where there was no change (either they were taking medications in both settings or not taking medication in either
setting). Some participants (17.70%) experienced a change in psychotropic medication status in that 4.20% (5) of participants took medication in the facility but not in the community, and 13.30% (16) of participants took psychotropic medication in the community but not in the facility (as indicated in bold). In total there were 89 (74.2%) participants using psychotropic medications in the facility and 100 (83.3%) participants using psychotropic medications in the community. Psychotropic medication use was significantly higher in the community ($X^2$ McNemar= 4.26, $df=1$, $p = .03$) than in the facility.

Table 3

<table>
<thead>
<tr>
<th></th>
<th>Facility</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Psychotropic % (n)</td>
<td>No psychotropic % (n)</td>
</tr>
<tr>
<td>Psychotropic</td>
<td>70 (84)</td>
<td>13.30 (16)</td>
</tr>
<tr>
<td>No psychotropic</td>
<td>4.20 (5)</td>
<td>12.50 (15)</td>
</tr>
</tbody>
</table>

Note. Bolded values indicate the groups whose medication usage changed after relocating from facility to the community.

Cross tabulations of these data with the support levels from the interRAI ID are presented in Table 4. Among the 83 participants who took psychotropic medications in both settings, 28 (33%) of them required extensive support. Among the individuals who belonged to the group where psychotropic medication was used in the facility but not the community, frequent, extensive and pervasive levels of support were equally required. Half of the individuals who took medication in the community, but not in the facility required extensive levels of support.
PSYCHOTROPIC MEDICATION USE

Table 4

Cross Tabulation of the SIBR and Psychotropic Medication Groups

<table>
<thead>
<tr>
<th>SIBR level of support</th>
<th>Facility only (n = 4)</th>
<th>Community only (n = 16)</th>
<th>Both (n = 83)</th>
<th>Neither (n = 14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
<td></td>
</tr>
<tr>
<td>Intermittent</td>
<td>0 (0)</td>
<td>6.25 (1)</td>
<td>1.2 (1)</td>
<td>7.1 (1)</td>
</tr>
<tr>
<td>Limited</td>
<td>0 (0)</td>
<td>6.25 (1)</td>
<td>7.2 (6)</td>
<td>7.1 (1)</td>
</tr>
<tr>
<td>Frequent</td>
<td>25.0 (1)</td>
<td>18.75 (3)</td>
<td>27.7 (23)</td>
<td>35.7 (5)</td>
</tr>
<tr>
<td>Extensive</td>
<td>25.0 (1)</td>
<td>50.0 (8)</td>
<td>33.7 (28)</td>
<td>28.6 (4)</td>
</tr>
<tr>
<td>Pervasive</td>
<td>50.0 (2)</td>
<td>18.75 (3)</td>
<td>30.1 (25)</td>
<td>21.4 (3)</td>
</tr>
</tbody>
</table>

Note. There are three missing SIBR scores and therefore the total n does not correspond to the total n in the psychotropic medication group chart.

Table 5 shows the cross tabulations for the BPI (standardized scores) and the 4 medication groups. The highest level of BPI scores are associated with the stereotyped behaviour severity and frequency subscales and the groups with no change in psychotropic medication use across setting - meaning those who take the most medications. The lowest BPI scores are associated with those participants who took psychotropic medications in the facility, but not in the community.
Table 5

Comparison of BPI (standardized) Means Across Psychotropic Medication Groups

<table>
<thead>
<tr>
<th>BPI scale</th>
<th>Facility only (n = 4)</th>
<th>Community only (n = 16)</th>
<th>Both (n = 83)</th>
<th>Neither (n = 14)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M(SD)</td>
<td>M(SD)</td>
<td>M(SD)</td>
<td>M(SD)</td>
</tr>
<tr>
<td>SIB frequency</td>
<td>0.25 (0.3)</td>
<td>0.31 (0.32)</td>
<td>0.34 (0.33)</td>
<td>0.22 (0.36)</td>
</tr>
<tr>
<td>SIB Severity</td>
<td>0.15 (0.14)</td>
<td>0.21 (0.2)</td>
<td>0.25 (0.3)</td>
<td>0.6 (0.21)</td>
</tr>
<tr>
<td>Stereotyped frequency</td>
<td>0.63 (0.59)</td>
<td>0.48 (0.41)</td>
<td>0.79 (0.75)</td>
<td>0.75 (0.77)</td>
</tr>
<tr>
<td>Stereotyped severity</td>
<td>0.42 (0.37)</td>
<td>0.30 (0.23)</td>
<td>0.45 (0.48)</td>
<td>0.46 (0.55)</td>
</tr>
<tr>
<td>Aggressive /destructive frequency</td>
<td>0.10 (0.16)</td>
<td>0.31 (0.36)</td>
<td>0.25 (0.35)</td>
<td>0.23 (0.26)</td>
</tr>
<tr>
<td>Aggressive /destructive severity</td>
<td>0.15 (0.20)</td>
<td>0.45 (0.68)</td>
<td>0.26 (0.37)</td>
<td>0.19 (0.21)</td>
</tr>
</tbody>
</table>

Table 6 shows the cross tabulation of the REISS scores across the psychotropic medication groups. A possible mental health problem was indicated for 27 participants who received a REISS above cut score. Twenty-two of the 27 participants were associated with the above cut score and medications and both settings. This is an expected finding as a majority of individuals who showed a mental health indicator were also taking psychotropic medication across both settings. In addition, four individuals who have a REISS score above cut-off were also associated with medication use in the community but not in the facility.

Table 6

Cross Tabulation of REISS Above Cut Scores and Psychotropic Medication Groups

<table>
<thead>
<tr>
<th>Setting of psychotropic medication usage</th>
<th>Facility only (n = 4)</th>
<th>Community only (n = 16)</th>
<th>Both (n = 82)</th>
<th>Neither (n = 14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Above cut scores</td>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td></td>
<td>.0 (0)</td>
<td>25.0 (4)</td>
<td>26.80 (22)</td>
<td>7.10 (1)</td>
</tr>
</tbody>
</table>

REISS total scores have also been cross tabulated with the four psychotropic medication groups (see Table 7). High mean scores are associated with those participants who took medication...
in the community but not the facility. Second highest mean scores are found in the group that took medication in both settings.

Table 7

Cross tabulation of REISS Total Scores and Psychotropic Medication Groups

<table>
<thead>
<tr>
<th>Setting of psychotropic medication usage</th>
<th>Facility only (n = 4)</th>
<th>Community only (n = 16)</th>
<th>Both (n = 82)</th>
<th>Neither (n = 14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>M (SD)</td>
<td>3.0 (2.9)</td>
<td>9.3 (1.6)</td>
<td>6.1 (6.0)</td>
<td>4.0 (3.3)</td>
</tr>
</tbody>
</table>

Mean scores for the number of years participants were out of the facility is comparable across groups, as is the variability across participants in each group (see Table 8). The highest mean (3.7) was among those participants who did not need medication in either setting. The lowest mean (2.5) was among those who used medication in the facility, but not in the community.

Table 8

Cross Tabulation of Time Out of the Facility and Psychotropic Medication Groups

<table>
<thead>
<tr>
<th>Setting of psychotropic medication usage</th>
<th>Facility only (n = 5)</th>
<th>Community only (n = 16)</th>
<th>Both (n = 84)</th>
<th>Neither (n = 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>M (SD)</td>
<td>2.5 (0.7)</td>
<td>3.5 (1.6)</td>
<td>3.24 (1.3)</td>
<td>3.7 (0.6)</td>
</tr>
</tbody>
</table>

Psychotropic Medication Use

To further examine psychotropic medication use, Table 9 shows it simplified into three categories. Category (1) shows total number of psychotropic medication use, category (2) shows the daily number of psychotropic medication use, and category (3) shows PRN psychotropic number medication use. Under each category there are descriptive statistics for two samples: (a) the total
sample of 120 participants, and (b) the italicized sample of 120 participants with cases of those who did not take psychotropic medication selected out. As such, the sample size will vary under each category.

Few differences were seen regarding the total number of psychotropic medication use among participants in the facility and the community (facility $M=2.01$ and community $M=2.1$). Even when cases of those who exclusively took psychotropic medications are computed (facility $M=2.6$ and community $M=2.5$), the means are still very similar. Total number of medication use in the facility had a slightly higher range of 0-7 psychotropic medications use in comparison to the 0-6 in the community. A paired samples t test shows no significant difference among medication use between the facility and community settings ($t = -.87, df = 119, p = .389$).
Table 9

*Psychotropic Medication Use for the Total Sample in Last Facility and First Community Assessments*

<table>
<thead>
<tr>
<th>Category 1</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Number of Psychotropic Medication</td>
<td>Facility</td>
<td>120</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Community</td>
<td>120</td>
<td>0</td>
<td>6</td>
<td>2.1 (1.5)</td>
</tr>
<tr>
<td>Facility</td>
<td>89</td>
<td>1</td>
<td>7</td>
<td>2.7 (1.4)</td>
</tr>
<tr>
<td>Community</td>
<td>100</td>
<td>1</td>
<td>6</td>
<td>2.5 (1.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category 2</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Number of Psychotropic Medication</td>
<td>Facility</td>
<td>120</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Community</td>
<td>120</td>
<td>0</td>
<td>6</td>
<td>1.89 (1.63)</td>
</tr>
<tr>
<td>Facility</td>
<td>85</td>
<td>1</td>
<td>5</td>
<td>2.15 (1.08)</td>
</tr>
<tr>
<td>Community</td>
<td>79</td>
<td>1</td>
<td>6</td>
<td>2.87 (1.10)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category 3</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Psychotropic PRN Medication</td>
<td>Facility</td>
<td>120</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Community</td>
<td>120</td>
<td>0</td>
<td>2</td>
<td>.20 (.46)</td>
</tr>
<tr>
<td>Facility</td>
<td>41</td>
<td>1</td>
<td>4</td>
<td>1.4 (1.67)</td>
</tr>
<tr>
<td>Community</td>
<td>21</td>
<td>1</td>
<td>1</td>
<td>1 (.000)</td>
</tr>
</tbody>
</table>

Daily psychotropic medication use was higher in the community \((M=1.89)\) than in the facility \((M=1.53)\). A paired samples t test showed that participants in the community had more frequent daily medications than in the facility \((t=-3.30, df=119, p=.001)\).

PRN use was higher in the facility \((M=.48)\) than in the community \((M=.20)\) A paired t test was performed across groups to test for significance. Results showed that PRN use was significant among participants in the facility than participants in the community \((t=3.346, df=119, p=.001)\).

In summary, the total number of psychotropic medications used stayed consistent across settings,
yet participants in the facility had higher PRN usage than those in the community and participants in the community had a higher daily medication usage than those in the facility.

**Common PRNs.**

The most common PRN medications used across facility and community settings is shown in Table 10. Lorazepam was the most frequently used PRN, with 39 participants in the facility (32.5 %) and 16 participants in the community (13.3 %). Diazepam was the second most commonly used PRN, with 6 participants in the facility and only one participant in the community. Some psychotropic medications, such as clonazepam, haloperidol, oxazepam, prochlorperazine, temazepam and zopiclone, were used in the facility as a PRN, but were not used in the community.

Table 10

**PRN Psychotropic Medication Use**

<table>
<thead>
<tr>
<th>PRN</th>
<th>Facility % (n)</th>
<th>Community % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chlorpromazine</td>
<td>2.5 (3)</td>
<td>.8 (1)</td>
</tr>
<tr>
<td>Clonazepam</td>
<td>2.5 (3)</td>
<td>0</td>
</tr>
<tr>
<td>Diazepam</td>
<td>4.9 (6)</td>
<td>.8 (1)</td>
</tr>
<tr>
<td>Haloperidol</td>
<td>.8 (1)</td>
<td>0</td>
</tr>
<tr>
<td>Lorazepam</td>
<td>32.5 (39)</td>
<td>13.3 (16)</td>
</tr>
<tr>
<td>Olanzapine</td>
<td>0</td>
<td>1.6 (2)</td>
</tr>
<tr>
<td>Oxazepam</td>
<td>.8 (1)</td>
<td>0</td>
</tr>
<tr>
<td>Prochlorperazine</td>
<td>.8 (1)</td>
<td>0</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>0</td>
<td>2.5(3)</td>
</tr>
<tr>
<td>Risperidone</td>
<td>0</td>
<td>.8 (1)</td>
</tr>
<tr>
<td>Temazepam</td>
<td>.8 (1)</td>
<td>0</td>
</tr>
<tr>
<td>Zopiclone</td>
<td>.8 (1)</td>
<td>0</td>
</tr>
</tbody>
</table>

A closer look at the individual psychotropic medications used in the last facility and first community assessments showed that all five classes of psychotropic medications used in the NIMH list were prevalent among participants in the facility and the community (see tables 11 - 15). These include antianxiolytics, antipsychotics, antidepressants, mood stabilizers and anticonvulsants, and
ADHD medications. There were significant changes in the class of psychotropic medication used across settings.

**Antianxiolytics.**

There were more participants using antianxiety medications in the facility (52.5%) than in the community (37.5%), \(X^2\) McNemar=6.57, \(df=1\), \(p=.01\) (see table 11). Among this class, more participants used lorazepam in the facility (40.8%) than in the community (22.5%). The least utilized psychotropic medication within the antianxiety class was zopiclone (1.7%) and temazepam (1.70%). Data shows that 32 participants were on antianxiety medications across both settings. There were 31 participants who took antianxiety medications in the facility, but did not take them in the community. Thirteen participants started antianxiety medications in the community.

Table 11

| Antianxiety Medication Use at Last Facility and First Community Assessment |
|-----------------------------|-----------------------------|-----------------------------|
| Facility | Community |
| % (n) | % (n) |
| **Antianxiety** | | |
| Buspirone | 10 (12) | 3.3 (4) |
| Clonazepam | 5.0 (6) | 9.2 (11) |
| Diazepam | 8.3 (10) | 2.5 (3) |
| Lorazepam | 40.8 (49) | 22.5 (27) |
| Oxazepam | 6.7 (8) | 5.0 (6) |
| Temazepam | 1.7 (2) | 2.3 (3) |
| Zopiclone | 1.7 (2) | .8 (1) |

Note: the first medication listed is the class (antianxiety), this number is a unique identifier showing how many participants used antianxiety medications \(n=120\).

**Antipsychotics.**

Participants in the community were significantly more likely to be taking antipsychotic medications (51.7%) than those in the facility, \(X^2\) McNemar=5.33, \(df=1\) and \(p = .02\), see Table 12.
Within the class of antipsychotic medications, the most frequently prescribed medication was risperidone (23.3%), quetiapine (14.2%) and olanzapine at (1.7%). No participants in the community sample were reported to take prochlorperazine. Haloperidol use decreased from 4.2% (facility) to 1.7% (community). Many participants were on antipsychotic medications in both settings (42) but 7 participants took antipsychotics in the facility but not in the community, while 20 participants were taking antipsychotic medications in the community.

Table 12

Antipsychotic Medication Use at Last Facility and First Community Assessment

<table>
<thead>
<tr>
<th>Antipsychotic Medication</th>
<th>Facility % (n)</th>
<th>Community % (n)</th>
<th>Test Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antipsychotic</td>
<td>40.8 (49)</td>
<td>51.7 (62)</td>
<td>$X^2$ McNemar=5.33, $df=1, p &lt; .021$</td>
</tr>
<tr>
<td>Chlorpromazine</td>
<td>3.3 (4)</td>
<td>4.2 (5)</td>
<td></td>
</tr>
<tr>
<td>Haloperidol</td>
<td>4.2 (5)</td>
<td>1.7 (2)</td>
<td></td>
</tr>
<tr>
<td>Methotrimeprazine</td>
<td>5.8 (7)</td>
<td>5.0 (6)</td>
<td></td>
</tr>
<tr>
<td>Olanzapine</td>
<td>5.8 (7)</td>
<td>11.7 (14)</td>
<td></td>
</tr>
<tr>
<td>Perphenazine</td>
<td>.8 (1)</td>
<td>1.7 (2)</td>
<td></td>
</tr>
<tr>
<td>Pimozide</td>
<td>0 (0)</td>
<td>.8 (1)</td>
<td></td>
</tr>
<tr>
<td>Prochlorperazine</td>
<td>.8 (1)</td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>Quetiapine</td>
<td>5.0 (6)</td>
<td>14.2 (17)</td>
<td></td>
</tr>
<tr>
<td>Risperidone</td>
<td>20 (24)</td>
<td>23.3 (28)</td>
<td></td>
</tr>
<tr>
<td>Zuclopenthixol</td>
<td>.8 (1)</td>
<td>0 (0)</td>
<td></td>
</tr>
</tbody>
</table>

Note: the first medication listed is the class (antipsychotic), this number is a unique identifier showing how many participants used antipsychotics n=120.
### ADHD Medication Use at Last Facility and First Community Assessment

<table>
<thead>
<tr>
<th></th>
<th>Facility % (n)</th>
<th>Community % (n)</th>
<th>Test Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHD medications</td>
<td>0 (0)</td>
<td>0.83 (1)</td>
<td>(X^2) McNemar = 0.00, (df = 1), (P = 1.00)</td>
</tr>
<tr>
<td>Methylphenidate</td>
<td>0 (0)</td>
<td>.8 (1)</td>
<td></td>
</tr>
</tbody>
</table>

Note: the first medication listed is the class (ADHD), this number is a unique identifier showing how many participants used ADHD medications \(n=120\).

**ADHD Medications.**

No participants took ADHD medications in the facility, and only one participant was taking ADHD medications in the community (see Table 13).

**Antidepressants.**

There were significantly more participants using antidepressants in the community (32.5%) than in the facility (19.2%) \(X^2\) McNemar = 11.25, \(df = 1\), \(p < .001\) (see table 14). The most frequently prescribed psychotropic medications in the community were citalopram (10%), trazodone (5%), fluoxetine (4.2%) and paroxetine (4.2%).
Table 14

Antidepressant Medication Use at Last Facility and First Community Assessment

<table>
<thead>
<tr>
<th>Antidepressant</th>
<th>Facility % (n)</th>
<th>Community % (n)</th>
<th>Test Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>X² McNemar=11.250, df = 1, p &lt; .000</td>
</tr>
<tr>
<td>Antidepressant</td>
<td>19.2 (23)</td>
<td>32.5 (39)</td>
<td></td>
</tr>
<tr>
<td>Citalopram</td>
<td>2.5 (3)</td>
<td>10 (12)</td>
<td></td>
</tr>
<tr>
<td>Amitriptyline</td>
<td>1.7 (2)</td>
<td>.8 (1)</td>
<td></td>
</tr>
<tr>
<td>Clomipramine</td>
<td>1.7 (2)</td>
<td>3.3 (4)</td>
<td></td>
</tr>
<tr>
<td>Doxepin</td>
<td>.8 (1)</td>
<td>.8 (1)</td>
<td></td>
</tr>
<tr>
<td>Fluoxetine</td>
<td>4.2 (5)</td>
<td>4.2 (5)</td>
<td></td>
</tr>
<tr>
<td>Fluvoxamine</td>
<td>.8 (1)</td>
<td>.8 (1)</td>
<td></td>
</tr>
<tr>
<td>Imipramine</td>
<td>0 (0)</td>
<td>.8 (1)</td>
<td></td>
</tr>
<tr>
<td>Paroxetine</td>
<td>3.3 (4)</td>
<td>4.2 (5)</td>
<td></td>
</tr>
<tr>
<td>Sertraline</td>
<td>3.3 (4)</td>
<td>2.5 (3)</td>
<td></td>
</tr>
<tr>
<td>Trazodone</td>
<td>1.7 (2)</td>
<td>5.0 (6)</td>
<td></td>
</tr>
<tr>
<td>Venlafaxine</td>
<td>0 (0)</td>
<td>2.5 (3)</td>
<td></td>
</tr>
</tbody>
</table>

Note: the first medication listed is the class (antidepressants), this number is a unique identifier showing how many participants used antidepressant medications n=120.

Mood stabilizers / anticonvulsants.

There were no statistically significant differences among participants’ use of mood stabilizers and anticonvulsants across settings (see Table 15). Mood stabilizer and anticonvulsant use in the facility was reported at 39.2% and 45.0% in the community sample.
Table 15

**Mood stabilizer / Anticonvulsant Medication Use at Last Facility and First Community Assessment**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Facility % (n)</th>
<th>Community % (n)</th>
<th>Test Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mood stabilizer / anticonvulsant</td>
<td>39.2 (47)</td>
<td>45.0 (54)</td>
<td>$X^2$ McNemar = 1.57, df=1, $P = .210$</td>
</tr>
<tr>
<td>Carbamazepine</td>
<td>23.3 (28)</td>
<td>21.7 (26)</td>
<td></td>
</tr>
<tr>
<td>Clobazam</td>
<td>5.0 (6)</td>
<td>5.8 (7)</td>
<td></td>
</tr>
<tr>
<td>Divalproex</td>
<td>21.7 (26)</td>
<td>23.3 (28)</td>
<td></td>
</tr>
<tr>
<td>Gabapentin</td>
<td>.8 (1)</td>
<td>.8 (1)</td>
<td></td>
</tr>
<tr>
<td>Lamotrigine</td>
<td>3.3 (4)</td>
<td>5.8 (7)</td>
<td></td>
</tr>
<tr>
<td>Lithium carbonate</td>
<td>3.3 (4)</td>
<td>5.0 (6)</td>
<td></td>
</tr>
<tr>
<td>Topiramate</td>
<td>2.5 (3)</td>
<td>5.8 (7)</td>
<td></td>
</tr>
</tbody>
</table>

Note: the first medication listed is the class “mood stabilizer / anticonvulsant”; its number is a unique identifier showing how many participants used mood stabilizer / anticonvulsant medications n=120.

A cross-tabulation of participants who were reported to have epilepsy and those who took mood stabilizers / anticonvulsants is found in Table 16. In the facility, among a total of 119 participants, 47 were reported to be taking a mood stabilizer / anticonvulsant, while 33 participants (27.7%) had epilepsy and were also taking a mood stabilizer / anticonvulsant. In the community, among a total of 120 participants, 54 participants were reported to have been taking mood stabilizers and anticonvulsants, while 41 participants (34.1%) had epilepsy and were also taking a mood stabilizer / anticonvulsant. A total of 39 participants were taking mood stabilizers / anticonvulsants in both settings. There was some change across settings, in that eight participants had taken mood stabilizer / anticonvulsant medication in the facility but had not taken it in the community, and 15 participants had taken mood stabilizer / anticonvulsant medication in the community but had not taken it in the facility. These are somewhat explained by the fact that 14 people had a change in epilepsy/seizure status in the community and 14 people no longer reported to have epilepsy / seizures in the facility. Our findings may also suggest that some participants were using mood stabilizers / anticonvulsants for other purposes than to treat epilepsy, as there were 14 participants in...
the facility and 13 participants in the community who did not have a diagnosis of epilepsy but who still took a mood stabilizer / anticonvulsant.

Table 16

*Epilepsy Diagnosis in the Last Facility and First Community Assessments*

<table>
<thead>
<tr>
<th>Class</th>
<th>Facility n=119</th>
<th>Community n=120</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Epilepsy % (n)</td>
<td>No Epilepsy % (n)</td>
</tr>
<tr>
<td>Mood stabilizer / anticonvulsant</td>
<td>27.7 (33)</td>
<td>11.8 (14)</td>
</tr>
<tr>
<td>Not taking a mood stabilizer / anticonvulsant</td>
<td>24.5 (29)</td>
<td>36 (43)</td>
</tr>
</tbody>
</table>

Tables 17 and 18 show further descriptive statistics on the class of psychotropic medications, so as to provide a clear picture of the frequency of medications within classes an individual received. For example, Table 17 shows that some participants were taking 5 mood stabilizers / anticonvulsants. The table also shows that there were participants taking up to 5 antianxiety medications. Looking at the same classes in the community, there were participants taking 3 mood stabilizers and 3 antianxiety medications. The least used class is ADHD medications.
Table 17

*Descriptive Statistics for Psychotropic Medication Classes in the Last Facility Assessment*

<table>
<thead>
<tr>
<th>Psychotropic class</th>
<th>Facility</th>
<th>Min</th>
<th>Max</th>
<th>M</th>
<th>(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antipsychotic</td>
<td></td>
<td>0</td>
<td>4</td>
<td>0.53</td>
<td>0.74</td>
</tr>
<tr>
<td>Antidepressant</td>
<td></td>
<td>0</td>
<td>2</td>
<td>0.20</td>
<td>0.42</td>
</tr>
<tr>
<td>Mood stabilizer/anticonvulsant</td>
<td></td>
<td>0</td>
<td>5</td>
<td>0.73</td>
<td>1.1</td>
</tr>
<tr>
<td>Antianxiety</td>
<td></td>
<td>0</td>
<td>5</td>
<td>0.94</td>
<td>1.2</td>
</tr>
<tr>
<td>ADHD</td>
<td></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

*Note: n=120*

Table 18

*Descriptive Statistic for Psychotropic Medication Classes in the First Community Assessment*

<table>
<thead>
<tr>
<th>Psychotropic class</th>
<th>Community</th>
<th>Min</th>
<th>Max</th>
<th>M</th>
<th>(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antipsychotic</td>
<td></td>
<td>0</td>
<td>4</td>
<td>0.57</td>
<td>0.8</td>
</tr>
<tr>
<td>Antidepressant</td>
<td></td>
<td>0</td>
<td>3</td>
<td>0.34</td>
<td>0.62</td>
</tr>
<tr>
<td>Mood stabilizer/anticonvulsant</td>
<td></td>
<td>0</td>
<td>4</td>
<td>0.78</td>
<td>1</td>
</tr>
<tr>
<td>Antianxiety</td>
<td></td>
<td>0</td>
<td>3</td>
<td>0.52</td>
<td>0.77</td>
</tr>
<tr>
<td>ADHD</td>
<td></td>
<td>0</td>
<td>1</td>
<td>0.03</td>
<td>0.12</td>
</tr>
</tbody>
</table>

*Note n=120*

**Combinations of Psychotropic Medications**

Table 19 presents results on the most utilized combinations of psychotropic medications. The most frequent combination in the facility among 17 (14.2%) participants is the antipsychotic + mood stabilizer/anticonvulsant + antianxiety combination. Only 9 participants (7.5%) used this combination of classes in the community. In addition, 10 participants (8.3%) were taking a different combination of psychotropic medications, namely mood stabilizer/anticonvulsant + antianxiety medication. The least likely combination used within the facility is antipsychotic + antidepressant combination (0.8%) and the antipsychotic + antidepressant + mood stabilizer/anticonvulsant combination (0.8%).
Table 19

Prevalence of Psychotropic Medication Combinations

<table>
<thead>
<tr>
<th>Combinations</th>
<th>Facility % (n)</th>
<th>Community % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antidepressant + antianxiety</td>
<td>2.5 (3)</td>
<td>5.8 (7)</td>
</tr>
<tr>
<td>Antidepressant + mood stabilizer / anticonvulsant</td>
<td>0.0 (0)</td>
<td>2.5 (3)</td>
</tr>
<tr>
<td>Antidepressant + mood stabilizer / anticonvulsant + antianxiety</td>
<td>3.3 (4)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td>Antipsychotic + Antianxiety</td>
<td>5.8 (7)</td>
<td>5.6 (6)</td>
</tr>
<tr>
<td>Antipsychotic + antidepressant</td>
<td>0.8 (1)</td>
<td>5.8 (7)</td>
</tr>
<tr>
<td>Antipsychotic + antidepressant + antianxiety</td>
<td>6.7 (8)</td>
<td>6.7 (8)</td>
</tr>
<tr>
<td>Antipsychotic + antidepressant + mood stabilizer / anticonvulsant + antianxiety</td>
<td>2.5 (3)</td>
<td>4.2 (5)</td>
</tr>
<tr>
<td>Antipsychotic + mood stabilizer / anticonvulsant + ADHD</td>
<td>0.0 (0)</td>
<td>0.8 (1)</td>
</tr>
<tr>
<td>Antipsychotic + antidepressant + mood stabilizer / anticonvulsant</td>
<td>0.8 (1)</td>
<td>3.3 (4)</td>
</tr>
<tr>
<td>Antipsychotic + mood stabilizer / anticonvulsant + antianxiety</td>
<td>14.2 (17)</td>
<td>7.5 (9)</td>
</tr>
<tr>
<td>Antipsychotic + mood stabilizer / anticonvulsant</td>
<td>5.6 (6)</td>
<td>10 (12)</td>
</tr>
<tr>
<td>Mood stabilizer / anticonvulsant + antianxiety</td>
<td>8.3 (10)</td>
<td>5.8 (7)</td>
</tr>
</tbody>
</table>

Note. This chart only includes combinations of psychotropic medications not the prevalence of participants using individual medications.

The results indicate that 12 participants (10%) were taking antipsychotic + mood stabilizer / anticonvulsant medications. Following this, the second most frequent combination was the antipsychotic + mood stabilizer / anticonvulsant + antianxiety medication, where 9 (7.5%) participants were prescribed it. The least frequent combination used by participants in the community was the antipsychotic + mood stabilizer / anticonvulsant + ADHD medications. No participants in the facility used a psychotropic medication within the ADHD class, as a result of this, the sample size was too small to perform any statistical tests.

Combinations that stayed consistent across group are the antipsychotic + antidepressants + antianxiety combinations where 8 (6.7%) participants were prescribed that combination in both settings.
Mental Health Diagnoses and Contact with Health and Mental Health Supports

The percentage of participants with a mental health diagnosis is shown in Figure 2. Although there appears to be slight differences regarding anxiety, mood and cognitive challenges (delirium dementia and amnesia) across settings, none of these trends is statistically significant (cognitive disorder, $X^2$ McNemar = .57, $df=1$, $p = .45$, schizophrenia $X^2$ McNemar = 0, $df=1$, $p = 1.00$, mood disorder $X^2$ McNemar = 0, $df=1$, $p = 1.00$, or an anxiety disorder $X^2$ McNemar = 1.33, $df = 1, p = .25$).

![Figure 2. Mental Health Diagnoses at Last Facility and First Community Assessment](image)

A summary of participants’ contact with health and mental health supports is reported in Table 20. 91.7% of participants in the facility and community had a physical within the last year. More participants in the community (91.7%) had a physician review their medication than in the community (80.7%). Significantly more participants in the community (70.7%) had seen a physician in the last three months than in the community (45%) ($X^2$ McNemar = 13.8, $df = 1$, $p = .00$). Participants in the community (18.3%) had significantly more contact ($X^2$ McNemar = 4.0, $df = 1$, $p = .046$) with a mental health worker during the past three months than participants in the facility (9.2%). A mental health worker may be a psychiatrist, psychologist, social worker etc.
More participants in the facility (31.7%) had a behaviour program within the past 3 months than in the community (22.5%).

Table 20

*Contact with Professionals*

<table>
<thead>
<tr>
<th>Contact with professionals</th>
<th>Facility % (n)</th>
<th>Community % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical exam in the past 12 months</td>
<td>91.7(110)</td>
<td>91.7 (110)</td>
</tr>
<tr>
<td>Physician reviewed whole med package in past 6 months</td>
<td>91.7(110)</td>
<td>80.7 (96)</td>
</tr>
<tr>
<td>Visit with a physician in the past 3 months</td>
<td>45 (54)</td>
<td>70.8 (85)</td>
</tr>
<tr>
<td>Visit with a mental health worker in the past 3 months</td>
<td>9.2 (11)</td>
<td>18.3 (22)</td>
</tr>
<tr>
<td>Behaviour management PROGRAM in the past month</td>
<td>31.7 (38)</td>
<td>22.5 (27)</td>
</tr>
</tbody>
</table>

*Note:* one participant is missing in each item, n=119.
Discussion

Introduction

The purpose of this study was to describe the use of psychotropic medication among 120 participants who transitioned from facilities to community settings in Ontario. Results show that psychotropic medication use in the community was significantly higher than psychotropic medication use in the facility. There were no significant changes of the total number of psychotropic medications used among participants, yet there were significant differences in the number of PRN’s used, the number of daily medications used and the class of psychotropic medications used. Community settings were also associated with an increase of participants diagnosed with an anxiety disorder and increased contact with a physician and or mental health worker within the last three months. The participants included in this study were adult males and females with a diagnosis of ID. This adult sample is consistent with other studies published on psychotropic medication and deinstitutionalization (Clarke et al., 1990; Robertson et al., 2000).

The instruments used to describe the demographics of this sample were the BPI, REISS and SIB-R adaptive scores. The adaptive behaviours were normally distributed across the ranges of support need that are expected in the population with ID. Both problem behaviours and mental health indicators were skewed, showing relatively low rates of symptoms at the time of measurement in the community, despite the high prevalence of psychotropic medication use. It is possible either the medication is achieving its desired effect in managing symptoms or perhaps some individuals remain on medications longer than necessary. These results are consistent with other studies (Branford, 1996). Overall there were low rates of problem behaviour as reported on the BPI. Yet participants did score high on the stereotypy subscales. Gowdey et al. 1897 did comment that community settings may be less likely to tolerate behaviours such as stereotypy, where as in an
institution environment they may go unnoticed. On the other hand, stereotypy may be likely to go untreated in community settings in comparison to aggression or self-injurious behaviours (R. Condillac, personal communication, March 24, 2012). This may be the case with our sample as our results show higher rates of stereotypy than rates of challenging behaviours (aggression, SIB). However, there is much variability among these scores. Nevertheless, the scores are low, which may be evidence that our sample was receiving effective treatment. The REISS scale assesses if a participant has indicators of a mental health problem. A cut score of nine or above is an indication of the aforementioned. Twenty-seven participants possessed a cut score of 9 or above on the REISS scale. Alternatively, 89 participants did not reach a cut score, indicating that the severity of their symptoms was not in the clinical range at the time of the assessment. This is a high percentage of individuals who did not have an indication of a dual diagnosis, given that 83% of the population took psychotropic medications.

Given that the BPI and REISS were conducted during the first community assessment, it is likely that participants were taking psychotropic medications when these assessments were conducted. This may have caused fewer participants to achieve a cut score and more participants to obtain lower scores on the BPI than if participants were not taking psychotropic medications at the time of these assessments. Also, 62 participants in this sample have a diagnosis of epilepsy.

**Psychotropic Medication Use**

This study reports on the prevalence of psychotropic medication use in four meaningful groups: (1) individuals who took psychotropic medication in the facility and community; (2) individuals who took medication in the facility but not in the community; (3) individuals who took medication in the community but not in the facility and (4) those who were not taking psychotropic medication at all. A majority of participants were in the groups with no change. However, many participants
started using psychotropic medication in the community but not in the facility. These results should be compared with caution to other studies, as many studies did not separate their participants into these groups. It would be interesting for there to be further investigation into the group where psychotropic medication increased in the community and what factors accounted for this increase.

A cross-tabulation between the REISS scores above cut-off and psychotropic medication groups (Table 6) demonstrate that four participants were in this category. It may be interesting to know if effects of the transition negatively influenced any of their mental health symptoms that may have resulted in the increased need for medication in the community. This is consistent with previously published literature. For example, Thinn et al. (1990) mentioned that some studies have found higher functioning individuals who regress and lower functioning individuals who show increased levels of adaptive and maladaptive behaviour 6-8 weeks after transition. Also, Hemming et al. (1981) discuss the implications of psychotropic medication use at four, nine, twelve and twenty-four months after relocation.

In the present study, the length of time out of facility ranged between 0-6 years. The mean time out of the facility was 3.3 years. Thinn et al. (1990) suggested that some participants require an increase in night sedation 9 and 12 months after transition. This study found no significant difference among groups regarding psychotropic medication use and their time out of the facility.

Mean psychotropic medication use resulted in 2.01 for participants in the facility and 2.1 for participants in the community. These results show that medication use for participants is similar across settings. This data included participants who were taking psychotropic and PRN medications together. Including PRN’s into the psychotropic medication count is different than that of Thinn et al. (1990) who did not include ‘as needed’ psychotropic medications in their count as they were not
given regularly. We also factored out the PRN use and reported only on daily medications; here we also found that daily psychotropic medication use was similar across settings.

Significant differences were found when looking at the class of psychotropic medication used across settings. Participants in the community used significantly more antipsychotics and antidepressants than participants in the facility. Participants in the facility used significantly more antianxiety medications than those in the community. ADHD medications were at very low rates across settings and mood stabilizers/anticonvulsants did not significantly change across settings.

PRN’s in the facility were on average 50% higher than in the community. Participants used lorazepam most often in the facility than in the community. This may also explain why the antianxiety medication is significantly higher in the facility than in the community. Another interesting finding is regarding daily psychotropic medication use in the community setting. Participants were more often taking PRN’s in the facility and taking daily medications in the community.

Different patterns of use across specific medication classes were found. In particular, participants in the community used significantly more antipsychotics and antidepressants than participants in the facility, while participants in the facility used significantly more antianxiety medications than those in the community. It is possible that some aspects of relocation and/or changes in routine have resulted in the medication changes. Past research has shown high rates of antipsychotic use in a community setting (Burd et al., 1991; Lunsky & Elserafi, 2012). This raises questions about prescribing practices and the use of antipsychotic medications to treat challenging behaviour, even when it is not necessarily effective (Tyrer et al., 2008).

Within medication classes specific trends were found. Participants were taking more olanzapine and quetiapine in the community than the facility; however, rates of risperidone stayed at
similar rates across settings, but rates of haloperidol decreased. This shows a trend towards a different generation of antipsychotics. Within the antidepressants, citalopram use increased in the community. Antianxiety medications were the only class significantly higher in the facility than the community. However, participants’ use of lorazepam stayed similar across settings.

It is possible that participants experienced some difficulty with the transition or adapting to a new environment. This notion is consistent with the literature - Hemming et al. (1981). Quetiapine and olanzapine are typically used to treat schizophrenia, but data suggested that the diagnosis of schizophrenia did not significantly increase among participants in the community setting. Studies suggest that an increase in psychotropic medications should be associated with an increase in psychiatric diagnoses (Burd et al., 1991). Citalopram may have been given to help participants deal with their anxiety. Medical professionals may have prescribed psychotropic medications to help participants deal with the transition, but may have been reluctant to diagnose until after the effects of the transition.

**Mental Health Diagnoses and Contact with Health and Mental Health Professionals**

Patterns regarding psychiatric diagnoses show that there were no significant differences regarding psychiatric diagnoses across settings. It is an interesting finding given that the rates of psychotropic medications are significantly higher in the community setting. In a study by Nottestad and Linaker (1999), diagnoses of anxiety disorder remained the same before and after deinstitutionalization, but diagnoses of schizophrenia increased. There may be many reasons why psychiatric diagnoses did not increase in the community. It may be that our participants did not fit the clinical profile or that they did not have access to professionals who diagnose or who felt comfortable diagnosing mental health issues within this highly complex population.
Data showed that participants in the community saw a physician and mental health worker significantly more in the past three months than individuals in the facility. These may be the individuals whose needs become higher in the community settings, or it may be an indication of the intensity of community supports. Also, relatively few participants have behaviour programs in place, which is unusual in a community setting with participants who have complex needs or high rates of behaviours and/or psychotropic medication use.

**Mood stabilizers and anticonvulsants**

Our results are consistent with the literature in that it is a common finding to see mood stabilizers and anticonvulsants (divalproex and carbamazepine) utilized similarly across settings (Fischbacher, 1987; Robertson et al., 2000). However, Clarke et al. (1990) did show in their study a higher use of antiepileptic medications in a facility setting than community-based settings.

**Combinations of Psychotropic Medications**

In this paper, instead of using the word polypharmacy the word ‘combinations’ is used. The word polypharmacy has many definitions in the literature and in many cases negative connotations. The word ‘combinations’ is a neutral term that describes more than one class of medication prescribed. Each setting had a different combination of psychotropic medication most often utilized by participants. In particular, the most common combination in the facility was the antipsychotic + mood stabilizer / anticonvulsant + antianxiety, and the most common combination in the community was the antipsychotic + mood stabilizer / anticonvulsant. It is expected that mood stabilizers would be prevalent in both combinations as it is one of the only classes not to change over time. There was another small set of participants taking antipsychotic + antidepressant + mood stabilizer /
antipsychotic + antianxiety. The number of participants taking this combination increased by 68% in the community. This is most concerning as it is the combination of medications with the most classes of psychotropic medications in it. A possible explanation for this may be that the persons taking these combinations may be the same participants who have an increased diagnosis of an anxiety disorder and/or participants who scored above cut score on the REISS. These may be the individuals who found it especially difficult to transition.

**Limitations**

A limitation of the present study is regarding the sample size. While a sample of 120 participants taking psychotropic medication is a good sample size, any analyses that grouped participants (e.g., participants who took psychotropic medication in both settings, participants who took medication in neither setting) resulted in groups that were too small to run further statistical analyses. A larger sample size would have allowed us to do further statistical tests to look at between-group comparisons.

Another limitation of the current study was in the documentation of the PRN medication on the interRAI. One codes the use of a PRN only if it has been used within the last three days. This may mean that the PRN count was higher for participants than was cited using the interRAI ID.

Also the interRAI ID has a previous version that was updated in 2006. This new version contains a section that inquires about epilepsy diagnosis and treatment. The 2005 version of the interRAI ID does not inquire about the treatment of epilepsy, only the diagnosis. Given that some participants used the 2005 interRAI ID, this study is unable to compare results regarding the treatment of epilepsy, which would have provided some clarification on whether the medication was prescribed to treat seizures, problem behaviour, or both.
The final limitation noted is the barrier with using the National Institute of Mental Health medication list. While it is a user-friendly list, it is not a comprehensive list of psychotropic medications. Medications were added to the list based on additional psychotropic medications occurring in the data set, and guidance was sought from skilled medical professionals to ensure accurate classification. A thorough list would have been preferable.

**Strengths**

This study is one of the only and most recent Canadian studies to look at psychotropic medication among individuals who have been relocated. There is a paucity of research using a longitudinal design when looking at psychotropic medication use and individuals with ID who have relocated. Therefore, a main strength of this study is in its research design.

This study provides useful information regarding prescribing practices in Ontario, common psychotropic medications used in Canada and information that may be of interest to medical teams practicing in this field. This study could be used to help inform growing services in Ontario, as there has been a lot of capacity built helping individuals who have been relocated to settle in Ontario. To further inform best practices in Ontario, this study may also serve as a basis for other studies to be conducted in Ontario regarding deinstitutionalization and psychotropic medication.

Evidence from this study facilitates the ability to compare some results to other studies conducted locally and abroad, especially since there have been inconsistent findings in the literature when looking at psychotropic medications across facility and community settings. This study adds to the growing body of research in this area.
Future research

Future research should serve to replicate this study with a greater sample size. An investigation into more information regarding the participants who started using psychotropic medication in the community may be fruitful in learning about the factors regarding medication use during transitions from a facility to a community-based setting. PRN medications should be included into the study, but analyses should also factor them out so the sample can be compared with and without them.

Building upon this research, it may help to know more information about the doses of psychotropic medications, diagnoses of these participants and why particular medications were prescribed. This is particularly important because many psychotropic medications are often used to inappropriately manage behaviour. Within the context of the present study, little implications can be gleaned regarding the appropriate or inappropriate use of psychotropic medications for this population. McGillivray and McCabe (2005) comment that physicians and psychiatrists may have different prescribing practices based on different environments (facility, community, respite options, family homes). For example, community-based physicians and psychiatrists may be less likely to prescribe antipsychotics than physicians and psychiatrists working in the community. The findings in this study do show different classes of medications associated with each environment. Prescribing practices may also differ within the country the research is conducted in. This may be another interesting area to investigate.

Summary and Conclusions

Overall, there were more people taking psychotropic medication in the community compared to the facility. However, there were no significant differences found in the total number of
psychotropic medication used. Significant differences and interesting findings were found in regard to class, combinations, PRN use and service utilization among these 120 individuals with ID. Little research has been conducted using a longitudinal design when looking at psychotropic medication among individuals who have been relocated. Therefore, this study should provide good compliment to the already existing literature by providing stepping stones to further investigations. These investigations go hand in hand with the many research projects, clinical services, networks of care and guidelines that have been established to help with providing best practice services to individuals who have been relocated in Ontario.
References Cited


