Pica among Persons with Intellectual Disability: Prevalence, Correlates, and Interventions

by

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AUTHOR’S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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ABSTRACT

Background: Individuals with intellectual disabilities (ID) have a higher prevalence of comorbid psychiatric disorders and challenging behaviours compared to the general population. Though less common, one area of concern among those with ID is pica (the ingestion of inedible substances)**.** To date, there is little knowledge of pica, particularly with respect to its risk factors and social consequences. The closure of Ontario's three remaining facilities by 2009 underscores the importance of having knowledge of complex behaviours such as pica for improving supports and services in the community for these individuals. The aim of this study is to better understand the characteristics and support needs of adults with ID and pica. This study is comprised of a quantitative and qualitative component.

Quantitative Study

Objectives: To investigate the prevalence, risk factors, social and medical characteristics of pica. To determine how pica is managed in terms of hours of supervision, receipt of interventions, and psychotropic medication.

Methods: Secondary data analysis was performed on two samples as part of cross-sectional study: 1008 persons with ID from Ontario's facilities and 420 community-dwelling adults with ID from southwestern Ontario. All persons had been assessed using the inter*RAI* Intellectual Disability (inter*RAI* ID)—a comprehensive and standardized instrument that measures a variety of domains for support planning. Bivariate and multivariate analyses were restricted to the facility sample due to the small size of persons with pica in the community.

Results: The overall prevalence of pica was 22.0% and 3.3% in the facilities and the community, respectively. Logistic regression analysis showed that being male, cognitive functioning, autism, and being non-verbal were associated with a higher odds of having pica, whereas activities of daily living (ADL) was a protective factor. A quadratic relationship was observed between cognitive function and pica: the risk of pica increased with severity of cognitive impairment up to moderate to severe levels of impairment and then diminished among those with very severe cognitive impairment. Behaviour management, self-care skills, and 8 hours or more of one-to-one supervision were more likely to be provided to persons with pica. Compared to persons without pica, persons with pica had higher rates of being prescribed antipsychotic medication. Surprisingly, pica was not associated with higher rates of gastrointestinal health problems, with the exception of acid reflux. The negative social outcomes of pica, however, were many: pica was associated with higher odds of not having a strong and supportive relationship with family, lack of contact with family or other close relations, and absence of participation in social and recreational activities.

Qualitative Study

Objective: To determine the support needs of adults with ID and pica from the perspective of direct-care staff of facility and community settings.

Methods: Through two focus groups, the perspectives of four staff from Huronia Regional Centre (HRC), and six staff from community agencies from southwestern Ontario were examined. Transcripts were analyzed thematically for factors that facilitated or hindered the management of pica.

Results: Qualitative data revealed three categories that underpinned reduction in pica: preventative measures (environmental controls, close supervision, and the provision of alternative activities), formal supports, and familiarity with the individual. On the other hand, inadequate staff support, lower functioning level of the individual, and lack of knowledge acted as barriers to managing and reducing pica. These barriers were associated with persons participating in fewer recreational activities and community outings, and in some cases the use of mechanical restraints. Barriers specific to each setting in the management of pica were also illuminated. Staff in both settings tended to be self-sufficient and isolated in managing this complex behaviour.

Conclusions: Results suggest that attention should be equally paid to the potential social consequences of pica rather than solely to its health risks. Higher staff to client ratios, and training and education for staff to provide more active support to promote individuals' engagement in recreational activity and community integration is needed. Key recommendations also focus on educating and training staff on the risk factors and appropriate management of pica. Improving the collaboration and knowledge exchange among developmental service agencies is also recommended to enhance the management of pica among caregivers. Lastly, the community at large needs education on pica to foster more inclusive community living for those with ID.

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1.0 Introduction

Individuals with an intellectual disability have a higher prevalence of comorbid psychiatric disorders and challenging behaviours compared to the general population (APA, 2000; Borthwick-Duffy, 1994). Though less common, one area of concern among this population is pica, the ingestion of inedible or nonnutritive substances. The term pica originates from the latin word for “magpie” (genus *PICA*), a bird known to have an appetite for a diversity of objects, including inedible objects (Parry-Jones & Parry-Jones, 1992). Common examples of pica include ingestion of paper, plastic, string, clothes, dirt, dust, cigarette butts, plastic, hair, paint, metal, rocks, foliage, and feces (Stiegler, 2005; Witkowski, 1990).

Although persons with dementia, pregnant women, individuals with sickle cell anemia, and those with psychiatric disorders are known to be at risk of pica, it is most frequently associated with intellectual disability (Ali, 2001, Parry-Jones & Parry Jones, 1992). In fact, pica is one of the most common eating disorders alongside obesity in individuals with ID, with reported prevalence rates varying from 0.2% to 25.8%; however, it is often suggested that pica is underidentified and underreported (Danford & Huber, 1981; Swift, Paquette, Davison, & Saeed, 1999; Tewari, Krishnan, Valsalan, & Roy, 1995).

The term intellectual disability or "ID" is being used in this thesis to refer to conditions and disorders, previously called "mental retardation", that are also called developmental disabilities, or intellectual and developmental disabilities (AAMR, 2006). ID represents a heterogeneous group of individuals rather than a specific illness or disease. It can be caused by numerous factors, including infections, genetic disorders, toxins, anoxia, malnutrition, and environmental deprivation. However, up to 40% of persons with ID have an undetermined etiology (APA, 2000). Despite this, these individuals do share two traits: below average intelligence and adaptive skills. The definition of ID used here follows the clinical definition in the DSM-IV-TR. The DSM-IV-TR defines ID using a combination of three factors: Intelligence Quotient (I.Q.) of approximately 70 or below; simultaneous "impairments in adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety"; and must be present before 18 years of age (APA, 2001). The American Association on Mental Retardation (AAMR) has further refined the definition of the diagnosis of ID and requires that the individual also be two standard deviations below the mean on a recognized test that measures conceptual, social, and practical skills, or a score of two standard deviations below the mean on one of these three domains in a standard recognized test (AAMR, 2002).

Pica is considered a self-injurious behaviour because of its associated health consequences. The health risks posed by pica include malnutrition, anemia, parasitic infections, oral and dental trauma, intestinal obstruction or perforation, and in severe cases death (Decker,1993; McLoughlin, 1988; Stiegler, 2005). Further, pica may be associated with disruptive or aggressive behaviour in some individuals (Danford & Huber, 1982; Bugle & Rubin, 1993). Thus, when combined with other challenging behaviours, pica can be particularly difficult to manage. Taken together, these consequences reveal that pica is a major health concern among those with ID and that it places tremendous demands on the support of family and caregivers.

Despite numerous studies on the prevalence and treatment of pica, there has been little interest shown in the risk factors and patterns of resource utilization among individuals with ID and pica. In particular, the amount and types of resources consumed by individuals with pica have not been adequately addressed despite the fact that the treatment of pica in those with ID has historically been intrusive and often involved physical restraint (Burke & Smith, 1999; Parry-Jones & Parry-Jones, 1992) Moreover, there are no empirical studies to date that have examined the social consequences of pica.

Currently, the Ministry of Community and Social Services (MCSS) plan to close the three remaining institutions in Ontario (MCSS, 2006). The transition of community support for these individuals highlights the importance of understanding pica and better ways to support individuals in the community. Community staff may not have the expertise or resources to support for adults with ID and pica. Hence, a better understanding of pica in adults with ID across community and institutional settings is essential. The goal of the present thesis is to investigate the prevalence, correlates, management patterns, and social consequences of pica among adults with ID in community and institutional settings. A second goal is to gain insights into caregivers' experiences, attitudes, ideas, and practices in supporting individuals with ID and pica using a qualitative approach. The experiences and viewpoints of caregivers could have an impact on the development and revision of guidelines and policies related to the management of pica by professionals, staff, and families. Moreover, this study will add to the skills and knowledge needed by community staff and families to manage and improve the quality of life of individuals with pica in the community.

The second section of this thesis will review the relevant literature regarding pica including the history, definition, prevalence, behavioural function, and consequences of pica. This will be followed by an examination of the risk factors, and other correlates of pica. A review of current treatment approaches for pica will also be discussed. In the final section, the general limitations of the existing literature will be acknowledged. In the third section, the purpose of the study and research objectives are presented. This study involves both quantitative and qualitative components and the methods and results of each will be presented separately.

2.0 Literature Review

2.1 Historical Perspective

Pica has been documented throughout history and is found worldwide. The Greeks were the first to document pica, specifically in the writings of Aristotle and Hippocrates. For example, Hippocrates associated cravings for soil with a problem within the blood. Parry-Jones and Parry Jones (1994) note that, from the mid 16th to the late 19th century, Europeans believed pica was caused either by chlorosis (iron deficiency anemia) or by the retention of impure blood due to the cessation of menses during pregnancy.

Sociocultural explanations of pica were also offered in the literature to explain pica among young women with chlorosis. As noted by Calmette in 1706, pica was encouraged by fashions and social pressures. For example, adolescent girls ate lime, coal, vinegar, and chalk because these substances were believed to produce a fashionably pale complexion. Historical evidence also indicates a symptom overlap between pica and anorexia nervosa in young girls such that the eating of non-nutritive or non-edible foods was an attempt to provide satiety and to reduce food intake in order to control body shape. Similarly, pica and bulimia have been found to co-occur for the same purpose (Parry-Jones & Parry-Jones, 1992).

Clay and soil eating were predominantly associated with “primitive” cultures (African tribes) in the 18th and 19th century rather than among Europeans. Pica was also observed frequently among the black slave population in the southern Unites States (Parry-Jones & Parry-Jones, 1992). This type of pica was believed to originate from malnutrition, hunger, and cultural beliefs about its supposed health benefits, though some asserted that mental causes played a factor, such as alienation and misery.

It wasn't until the 19th century during the asylum era that the link between pica and ID was first documented. Asylum case notes and textbooks on insanity noted that coprophagy (eating of feces) and coal eating was commonly observed in "idiots" (Parry-Jones & Parry Jones, 1992). At this time, pica was either attributed to their inability to discriminate between edible and nonedible substances, or to emotional deprivation, rather than to underlying biological causes. Concern for pica in infants and children with and without ID culminated in the 20th century with the finding that the chewing and swallowing of lead based items caused lead poisoning, brain damage, and death. Thus from a historical perspective, pica has been considered a manifestation of multiple conditions.

2.2 Definition and Types of Pica

There are various definitions of pica present in the literature. The Diagnostic Statistical Manual, fourth edition-text revision (DSM-IV-TR) defines pica as the persistent eating of nonnutritive substances for at least a month and must be: 1) developmentally inappropriate (beyond 18 to 24 months of age), 2) not a culturally based practice, 3) and a severe behaviour warranting clinical attention. According to the DSM-IV-TR, pica is a rare disorder with onset typically in the second year of life; it usually remits in childhood but may persist into adolescence. The diagnostic criteria for pica within the DSM-IV-TR have come under scrutiny in recent years. One of the strongest criticisms pertains to the high prevalence of the eating of clay and soil in particular cultures such as in Africans and African Americans in the southern United States, and the detrimental health effects it may have. However, Paniagua (2000) contends that too much emphasis on cultural variables may result in failure to identify severe psychiatric disorders and a failure to treat the medical complications such as hyperkalaemia, mineral deficiencies, and parasitic infections (Carter, Wheeler, & Mayton, 2004; Parry-Jones & Parry-Jones, 1992).

The tenth edition of the International Classification of Diseases (ICD-10) defines pica (F98.3) as “the persistent eating of non-nutritive substances,” although a time frame is not specified as in the DSM-IV-TR. It also states that although pica may be part of a psychiatric disorder or may be an isolated disorder, a primary diagnosis of pica should only be made for those who exhibit pica as an isolated disorder (World Health Organization, 2003). Therefore, the ICD-10 generally regards pica as a symptom of other disorders whereas the DSM-IV-TR tends to give pica the status of an isolated eating disorder. For instance, the ICD-10 may consider pica to be a symptom of autism or having an intellectual disability.

Researchers have extended the definition of pica to include some food items (e.g., rotten or frozen foods), non-ingestion (e.g., mouthing, licking, or sucking inedible objects), and a combination of these. As a consequence, there are inconsistent prevalence rates and findings concerning pica. For research and clinical clarity, a consensus is needed for the definition of pica, including what types of ingested substances are problematic, and what associated complications should be considered.

A controversy still remains as to whether pica should be considered an eating disorder or a challenging behaviour. The DSM-IV classifies pica as an eating disorder, whereas the ICD-10 classifies pica more as a problem behaviour. Many prominent researchers in the ID field, such as Emerson (2001), recognize pica as a challenging behaviour because it puts the physical safety of the person at risk, and likely limits their quality of life. Equally important in determining if a behaviour is challenging or not is dependent on how others perceive the behaviour, such as whether or not others can tolerate, change or minimize the consequences of the behaviour (Sigafoos, Arthur, O’Reilly, 2003). A final reason for labeling pica as a challenging behaviour is that the etiology of pica is largely unknown. For example, the mineral deficiency hypothesis is only correlational. For the remainder of this thesis, pica will be referred to as a challenging behaviour instead of as an eating disorder.

Types of Pica

While many individuals with ID and pica ingest a wide range of inedible substances, some individuals show a preference for particular types of substances. Several types of pica have been delineated in the literature and labeled according to the Greek word phagia, meaning “to eat,” preceded by the specific substance. Table A presents the different types of pica, although this does not encompass all of the potential substances ingested by those with ID. Pagophagia is the ingestion of ice. A considerable amount of evidence suggests that pagophagia is associated with anemia in the general population (Parry-Jones & Parry Jones, 1994). Coprophagia (ingestion of feces) is frequently found in institutional settings among individuals with ID and is associated with fece smearing (Lacey, 1990). Likewise, tobaccophagia (eating of cigarette butts) is also frequently reported in those with ID residing in institutions (Danford & Huber, 1982; Matson & Bamburg, 1999) Geophagia is the eating of clay or dirt and is most common in developing nations (e.g., Africa), African Americans, and in pregnant women in the southern United States (Henry & Kwong, 2002); however, geophagia has been reported in the ID population as well. Tricophagia (the ingestion of hair), is less frequently mentioned in the literature. On the other hand, acuphagia (the ingestion of sharp objects), is a potentially fatal behaviour, reported to occur in individuals with autism (Kinell, 1985) possibly due to sensory disturbances (Klinger, Dawson, & Renner, 2003).

Table A. Types of Pica.

Phagia	Substance
Acuphagia	sharp objects
Amylophagia	laundry starch
Coprophagia	feces
Cautopyreiophagia	burnt matches
Foliophagia	leaves, grass
Geophagia	sand, clay, dirt
Lignophagia	wood, bark, twigs
Lithophagia	stones and pebbles
Pagophagia	ice, freezer frost
Plumbophagia	lead items
Tobaccophagia	cigarettes butts
Trichophagia	hair

Note: Taken from Stiegler (2005)

2.3 Prevalence of Pica

The prevalence rates of pica vary depending on the definition, methodology, and the characteristics of the ID population being studied (i.e., severity of ID). Tables' B and C provide a summary of the main prevalence studies on pica in institutional and community settings, respectively. Several studies have attempted to determine the prevalence of pica; however, the majority have surveyed institutional populations and therefore community-based data are limited. Reported prevalence rates in the institutionalized ID population range from 5.7% to 25.8%, where higher rates are associated with a more inclusive definition of pica. In contrast to institutional figures, the prevalence rates in the community are much lower and range from 0.2% to 4.1%.

Rates for pica have also been examined among specific subgroups of persons with ID, namely those with challenging behaviours and psychiatric diagnoses. The most recent community-based studies have examined pica among individuals with ID and comorbid challenging behaviours or psychopathology. Prevalence rates of pica among adults with comorbid ID and challenging behaviour in the community are generally higher with rates ranging from a low of 11.0% to a high of 21.0% (Emerson, Kiernan, Alborz, Reeves, Mason, Swarbrick, Mason, Hatton, 2001; Joyce, Ditchfield, Harris, 2001). Dudley, Ahlgrim-Delzell, and Calhoun (1999) examined the prevalence rates of the psychiatric diagnoses and behaviour problems among a sample of 940 individuals with a dual diagnosis (i.e., co-existing ID and psychiatric disorder) and found that 3.7% exhibited pica. These estimates must be interpreted carefully, as these studies calculated prevalence based on individuals with challenging behaviours or a dual diagnosis, which can lead to inflated estimates; that is, these estimates do not represent those in the general population who have ID. Because of its clear impact on health and quality of life, pica behaviour among adults with ID warrants further attention. Further study is needed to determine the prevalence of pica among community-dwelling individuals with ID.

Table B. Prevalence Rates of Pica in Institutions Among Adults with ID

Study	Definition of Pica	Method	Sample Size	Level of ID (%)	Prevalence (%)
Danford & Huber (1982)	Consumption of non-food items and the excessive, compulsive eating of food and food-related substances	Staff interviews and direct observation over 2 years	n=991	78 profound 16 severe 4 moderate 2 mild	25.8 overall 16.7 non-food pica 5.4 food pica 3.7 both
McAlpine & Singh (1986)	Inedible or non-nutritive substance touching the person's lips, being placed in the mouth, or being ingested	Direct observation by staff across four different settings; and review of medical and personal files	n=607	76 profound 12 severe 12 moderate	9.2 overall
Lofts, Schroeder, Maier (1990)	The ingestion of non-food items	Review of medical records; individual habilitation plans; and individuals behaviour programs for behaviours of pica	n=806	62.5 profound 24.4 severe 10.4 moderate 2.3 mild	15.8 overall
Witkowski (1990)	Mouthing and/or ingestion of nonnutritive items	Direct observation and use of Pica Survey over 1 year	n=1010 (all females)	94.1 profound 4.1 severe 1.2 moderate 0.6 mild	16.7 overall 7.2 mouthing only 2.0 ingesting only 7.3 both 0.2 no information
Tewari et al. (1995)	Ingestion of non-food items and particular food substances (ice-cold food, food from rubbish bins, and discarded food)	Direct observation by nursing staff and review of case notes	n=246	84.0 severe learning disability 16.0 moderate disability	10.2 overall
Swift et al. (1999)	the frequent consumption of non-food and food-related substances	Survey questionnaire distributed to staff; residents' medical files	n=689	84.2 profound Note: Other ID levels not reported	22.1 overall 19.7 non-food pica 1.0 food pica 1.3 both
Matson & Bamburg (1999)	DSM-IV criteria: the eating of nonnutritive substances	Direct observation and psychological and functional assessments	n=790	86.7 profound 13.3 severe	5.7 overall

Table C. Prevalence Rates of Pica in the Community Among Adults with ID

Study	Definition of Pica	Method	Sample Size	Level of ID	Prevalence (%)
Rojahn (1986)	Not stated	Mail survey to caregivers	n=25,872	Not reported	0.2
O'Brien & Whitehouse (1990)	Eating non-food substances	Direct observation over a 28 day period; Semi-structured interview using the eating behaviour section of the Present Behavioural Examination-Mental Handicap	n=48	Moderate to severe; specific distribution not reported	4.1
Hove (2004)	Eating objects not considered to be food	Questionnaire	n=311	Mild to profound; specific distribution not reported	2.9

2.4 The Behavioral Function of Pica

Behavioural theorists believe that challenging behaviours exhibited by individuals with ID are initiated and maintained by a variety of causes or functions, including escape, attention, tangible reward, physical discomfort, and self stimulation or automatic reinforcement (Applegate, Matson, & Cherry, 1999). Recent research has focused on the behavioural function of feeding problems in persons with ID and reports that pica appears to be maintained predominantly by non-social reasons, rather than dependence on the social environment (Applegate et al., 1999; Matson et al., 1999; Matson, Mayville, Kuhn, Sturmey, Laud, Cooper, 2005). That is, the pica behaviour is self-reinforcing because of the sensory stimulation of the objects that are mouthed and ingested. According to Matson et al. (2005), individuals with ID and pica were significantly more likely to receive higher scores on a nonsocial subscale compared to individuals with other feeding problems not including rumination (i.e., aggression and self injurious behaviour during meal time, food refusal, food stealing). While the study points out that both pica and rumination primarily serve a self-stimulatory function compared to other maladaptive feeding problems, it is important to recognize that these behaviours are probably caused by multiple factors. For example, Matson et al. (1999) reported that individuals with pica displayed significantly fewer social skills, which may serve to maintain the pica behaviour, compared to those without pica. Also, Mace and Knight (1986) showed that the amount of available social interaction affected the rates of pica for one individual: social interaction was associated with lower levels of pica. Similarly, Piazza et al. (1998) reduced the occurrence of pica in one individual with the provision of social attention. These two cases run counter to the argument that pica is largely maintained by automatic reinforcement and point out that pica is maintained by factors unique to the individual.

2.5 Consequences of Pica

2.5.1 Medical Consequences

A broad range of health and social complications arise from pica and result in mild to life threatening health risks. The health consequences of pica fall into ten categories: malnutrition, toxicity, parasitic infections, gastrointestinal, obstructions and perforations, respiratory problems, dental injury, oral complications, and death. Social consequences include isolation, stigma, and burden on the support network. It is important to note that most individuals who swallow foreign objects are asymptomatic as the majority of foreign objects pass spontaneously through the gastrointestinal tract (Uyemura, 2005; Wahbeh, Wyllie, & Kay, 2002).

Malnutrition

Iron deficiency is the most commonly associated complication with pica (Ali, 2001; Danford, Smith, & Huber, 1981; Danford & Huber, 1982; Parry-Jones & Parry-Jones, 1994, Witkowski, 1990). One theory postulates that pica is a response to mineral deficiencies while another theory suggests that pica causes the mineral deficiencies by directly inhibiting the absorption of minerals. For example, zinc deficiency has also been reported in those with ID and pica in institutional settings (Lofts, Schroeder, & Maier,1990; Swift, Paquette, Davison, & Saeed, 1999), particularly in individuals who engaged in geophagia (Danford et al.,1981). This finding is consistent with the notion that soil/clay can chelate or inhibit the absorption of iron and zinc (Ali, 2001). Alternatively, pica may result in malnutrition because the individual eats non-nutritive substances rather than normal food, resulting in a reduction of appetite and body weight (Danford & Huber, 1981).

Toxicity

While rarely reported, pica may result in exposure to toxic materials such as heavy metals (Boris, Owen, & Steiner, 1996; Johnson, Hunt, & Siebert, 1994; Piazza, Hanley, Blakeley-Smith & Kinsman, 2000). The best known of these is lead toxicity and results from the ingestion of paint chips, house dust, ink, lead items, and soil contaminated with lead. Lead has deleterious effects on both cognitive and emotional functioning. Therefore, lead exposure may result in further brain damage and cause behavioural disturbances in those with ID. Although governments have implemented measures to reduce environmental exposure to lead, including controlling lead levels in paint, individuals with pica are still at risk.

Parasitic Infections

Pica has been linked to intestinal parasites, particularly for those who engage in coprophagia and geophagia (Foxx & Martin, 1975; Bugle & Rubin, 1993). For example, Foxx and Martin (1975) found three individuals with ID and coprophagaia who had whipworms; these individuals became parasite free after their pica decreased due to a behavioural intervention. In addition, Danford and Huber (1982) found that institutionalized individuals with ID and pica were significantly more likely to have pinworms than those without pica.

Gastrointestinal

Constipation and fecal impaction have been reported as symptoms of pica (Danford & Huber, 1982; Hoyte, 1997). Pica also causes abdominal distension, tenderness, pain, fever, vomiting, and nausea (Uyemura, 2005).

Obstructions and Perforations: Surgery

Surgical complications of pica, although uncommon, may occur. Decker (1993) reviewed the medical records of 35 patients with ID and pica from Huronia Regional Centre between 1976 and 1991 who were treated for pica related complications on 56 occasions. They found that 42 cases (75%) required surgical intervention, specifically laparotomies for the removal of foreign objects. Likewise, Anderson, Akmal, and Kittur (1991) reviewed 43 reported cases of surgical complication from pica in the literature. Intestinal obstruction was the most common complication, followed by perforation with peritonitis (inflammation of abdominal lining), and hardened abdominal masses (i.e., bezoars).

Some substances are more hazardous than others. Sharp and large objects are more likely to damage tissues and require surgery more often than smooth objects (e.g., coins, plastic beads) (Uyemura, 2005). For example, one study documented that vinyl gloves used for personal care are difficult to remove when ingested, because they become rigid and sometimes sharp bezoars (i.e., ball of foreign material that is unable to pass through the intestines). The resultant complications can include obstruction, perforation, inflammation, and ulceration of the gastrointestinal tract with bleeding (Kamal, Thompson, & Paquette, 1999).

Respiratory Problems

Foreign objects lodged in the esophagus may result in choking, respiratory distress, dyspnea, and wheezing (Uyemura, 2005). If foreign objects remain undetected in the esophagus they may lead to recurrent pneumonia (McLoughlin, 1988; Uyemura, 2005). Esophageal foreign bodies can also damage and perforate the esophagus and cause neck swelling.

Dental Injury

Pica has been linked to tooth surface loss in many case studies (Barker, 2005). In particular, dental injury may result from prolonged pica involving hard substances, such as stones, metals, or ice.

Oral Complications

Some individuals with pica prefer to ingest cigarette butts (Danford & Huber, 1982; Matson & Bamburg, 1999; Piazza, Hanley, & Fisher, 1996; Tewari et al., 1995). Consequently, they are at risk of developing oral cancer, periodontal disease, and gingival recession with chronic ingestion of cigarette butts.

Death

Individuals who engage in pica, particularly those with severe and persistent pica are at risk of death from intestinal obstruction and asphyxia. In a study examining the causes of death among 94 patients in a hospital for the developmentally delayed, 3 deaths (3.2%) were associated with pica (McLoughlin, 1988). Decker (1993) found that among 35 patients with pica admitted to a hospital over a period of 15 years, 4 patients (11%) died of pica related complications. Other case reports also note the high risk of mortality associated with pica (Dumaguing et al., 2003).

2.5.2 Social Consequences

Very little research has been conducted on the social consequences of pica. Individuals with pica may face increased stigma from others (Foxx & Martin, 1975; Steigler, 2005) and, as a result, may become more isolated. In particular, individuals with coprophagia (i.e., the ingestion of feces) are more likely to be avoided and excluded from activities as staff are afraid of cross-infection (Ali, 2001; Foxx & Martin, 1975). Pica and its associated behaviours may prevent the individual from participating in meaningful activities, or the protective equipment worn may restrict them from social interactions and engaging in activities (LeBlanc, Piazza, & Krug, 1997; Rojahn, Schroeder, & Mullick, 1980). Individuals with pica may also experience fewer community outings and/or may be prevented from going outside where potential substances for their pica behaviour are available. The demands of caring for a person with pica may also have consequences on the informal support network, such that persons with pica may have more conflict laden relationships and less social contact with family.

Collectively, these anecdotes suggest that individuals with pica may suffer from a poorer quality of life compared to those without pica. There is a need to increase the awareness of not only the medical complications associated with pica but, of its social consequences, in order to improve quality of life outcomes.

2.6 Risk Factors for Pica

It is unclear what causes pica, but most researchers postulate that its causes are multifactorial. The most common risk factors associated with pica include age, gender, severity of ID, mineral deficiencies, genetic syndromes associated with ID, psychiatric diagnoses, and social context, which increase the likelihood of individuals with ID to engage in pica.

2.6.1 Age

Rates of pica tend to be higher in younger rather than older individuals with ID (McAlpine et al., 1986; Danford et al., 1982; Tewari et al., 1995; Witkowski, 1990), though some have found they tend to be older (Dudley et al., 1999), or that the occurrence of pica increased after the age of 70 years (Danford et al., 1982), and others report no association with age

(Hove, 2004; Matson et al., 1999; Swift et al., 1999). Some researchers suggest that pica persists throughout the lifespan because it is often underidentified, underreported, and untreated because pica it is not viewed as problematic when compared to other challenging behaviours such as aggression (Danford et al., 1982; Witkowski, 1990).

Like the general population, individuals with ID are aging and the age structure of the population must be considered when examining the relationship between pica and age. As suggested by Emerson, Kiernan, Alborz, Reeves, Mason, Swarbrick, Mason, and Hatton (2001), earlier studies may have found a lower frequency of pica in older ages simply because of the younger age structure of the overall ID population. This is particularly true of persons with severe and profound levels of ID residing in institutions who are at greater risk of mortality compared to their higher functioning counterparts (Patja, Iivanainen, Vesala, Oksanen, Ruoppila, 2000). Individuals with ID are living longer compared to 20 or 30 years ago due to better standards of health care and living conditions. Therefore, estimates based on earlier cohorts with different age distributions may not pertain to the present. Alternatively, higher rates of pica observed among younger age groups with ID may be attributed to the fact that pica results in high morbidity and mortality and thus individuals with pica are less likely to live as long as those without pica. Given that the research in this area is cross-sectional in nature, longitudinal research is indeed warranted to better understand how age is related to pica.

2.6.2 Gender

Pica is diagnosed much more frequently in males than females, with the male to female ratio ranging from 1.3:1 to 2:1 (Lofts et al., 1990; Matson et al., 1999; McAlpine et al., 1986; Swift et al., 1999; Tewari et al., 1995). However, in a case-control study, Swift et al. (1999)

found that gender was not significantly related to pica. The higher occurrence of pica among males may simply reflect the fact that males outnumber females in institutions and more generally when it comes to the diagnosis of ID (APA, 2001).

2.6.3 Severity or Level of ID

Intellectual disability is generally divided into five categories indicating the severity of intellectual impairment: borderline, mild, moderate, severe, and profound. Severity is based on scores from standardized intelligence tests (e.g., Wechsler Intelligence Scales for children; Stanford-Binet; Kaufman Assessment Battery for Children) which produce an intelligence quotient (I.Q.). A “severity unspecified” category is used when there is strong presumption of mental retardation, but when one is unable to measure a person’s IQ due to a variety of factors (APA, 2000). See Table D below for the definition and proportion of each level of ID in the ID population.

Table D. ID Severity by I.Q. Score

ID Severity	I.Q. Score	Prevalence in ID population
Borderline	71-84	-
Mild	50-55 to 70	85%
Moderate	35-40 to 50-55	10%
Severe	20-25 to 35-40	3-4%
Profound	Below 20 to 25	1-2%
Unspecified	Strong presumption of mental retardation	-

Note: Taken from APA (2001)

The tendency for individuals with severe and profound levels of ID to exhibit pica more often than those with milder levels of ID is one of the most robust findings reported in the pica literature (Danford et al., 1982; Dudley et al., 1999; Lofts et al., 1990; Matson et al., 1999; McAlpine et al., 1986; Swift et al., 1999; Tewari et al., 1995; Witkowski, 1990). Specifically, level of ID (as measured by IQ) is negatively associated with the occurrence of pica such that the incidence of pica increases with severity of ID or lower IQ scores. Various explanations for this association have been offered in the literature and range from developmental mouthing difficulty related to the ID itself, to sensory stimulation, to the inability of individuals with severe cognitive impairment to discriminate edible from inedible items. Hove (2004) believes that pica may reflect adaptive skill deficiencies in eating and self-care in the ID population.

2.6.4 Mineral Deficiencies

Mineral deficiencies, including iron, zinc, copper, and magnesium have been linked to pica, particularly for persons in the general population. It is believed that low levels of minerals in the body cause an instinctive behavioural response or craving in individuals to seek out these minerals from unusual sources, such as in inedible objects (Ali, 2001). However, pica occurs often in the absence of mineral deficiencies (McAlpine & Singh, 1986; Witkowski, 1990) and most studies show that persons with ID and pica ingest substances with very low mineral content.

Danford et al. (1982) were among the first to examine the nutritional hypothesis of pica among persons with ID. They compared 60 individuals with pica to 6 individuals without pica and found that plasma iron and zinc levels were significantly reduced in those with pica, while copper and magnesium levels were not significantly different between the two groups. Similarly, Lofts et al. (1990) demonstrated in an institutional survey that 54% of individuals with pica (n=69) had low serum zinc levels (zinc levels less than 0.90 ug/dl) as compared to 7% of 14 individuals from the control group. Further, they found that zinc supplementation in the form of 100 milligrams of chelated zinc among those with ID, pica, and low serum zinc levels reduced the number of incidents of pica from 23 incidents per person to 4.3 incidents per person in a two-week period although it did not eliminate their pica entirely. Subsequently, Swift et al. (1999) built upon these previous two studies and produced one of the most carefully designed case-control studies in this area. Specifically, they compared the blood samples of 152 individuals with ID and pica to 152 controls with ID alone. They found that individuals with low serum zinc levels had 6.25 times the odds of having pica and individuals with low serum iron had 5.43 times the odds of having pica after adjusting for the person's level of ID. This is the first study to establish that mineral status is an independent risk factor for pica while taking into account the person's level of ID. Subsequent research will need to improve on this model and include all known risk factors for pica in order to obtain more valid estimates of the relation between mineral deficiencies and pica.

There appears to be a general consensus that pica is associated with mineral deficiency in the ID population, particularly deficiencies in zinc and iron; however, current case-control studies and case reports are unable to establish the causality of this relationship. The same is true for studies examining pica and mineral status in the general population. Due to the cross-sectional nature of most research in the area, it is unclear whether mineral deficiencies are a consequence or result of pica. To better understand this relationship, randomized controlled trials and longitudinal studies are needed.

2.6.5 ID Syndromes

Researchers have investigated whether various genetic disorders or syndromes contributing to ID are associated with pica. Pica has been shown to be implicated in autism and Prader-Willi syndrome.

2.6.5.1 Autism

The point prevalence of autism among adults with ID has been estimated at approximately 30.0% (Morgan, Roy, Nasr, Chance, Hand, Mlele, & Roy, 2002). Pica is common in individuals with autism (Dudley et al., 1999; Grewal & Fitzgerald, 2002; Hove, 2004; Kinnell, 1985; Matson & Bramburg, 1999; O'Brien & Whitehouse, 1990; Piazza, Hanley, & Fisher, 1996). In fact, Hove (2004) found that those with autism were more likely to engage in pica than other eating disorders, and another study revealed that individuals with pica were significantly more likely to have autism (Dudley et al., 1999). This finding is not surprising given that a recent review found that on average 55.5% of individuals with autism have severe to profound levels of ID, which is a well-known risk factor for pica (Fombonne, 1999). In addition, individuals with autism often have disturbed sensory systems and thus they may seek out inedible objects for their texture, colour, or taste for stimulation purposes (Klinger et al., 2003).

In a retrospective study, Kinnell compared 70 individuals with autism to 70 with Down's syndrome with respect to pica behaviour and found that individuals with autism (60%) were more likely to engage in pica than individuals with Down's syndrome (4%). Among the few with pica and Down's syndrome (4%), they also had either comorbid autism or schizophrenia. While it appears that pica might be syndrome-specific, this relationship has not yet been confirmed at the multivariate level (Swift et al., 1999).

2.6.5.2 Prader-Willi Syndrome

Prader-Willi syndrome (PWS) is a genetic disorder caused by abnormalities in chromosome 15 that often results in ID (Holland, Treasure, Coskeran, Dallow, 1995). The prevalence rate has not been reported for the ID population alone, but rather for the general population only. Food-seeking behaviour and hyperphagia seem to occur universally in PWS due to an impaired satiety response or dysfunction of their hypothalamus (Holland et al., 1995).While recent studies suggest that individuals with PSW are more likely to seek out salty, sweet, and/or high-carbohydrate foods compared to those without PSW (Fieldstone, Zipf, Schwartz, & Bernston, 1998; Glover, Maltzman, Williams, 1996; Young, Zarcone, Holsen, Anderson, Hall, Richman, Butler, Thompson, 2005), a few empirical studies have also revealed that a subgroup of these individuals engage in inappropriate consumption, such as pica (Dykens, 2000; Duker & Nielen, 1993). For example, Dykens surveyed 50 adolescents and adults with PWS with varying levels of ID and found that they were more likely to say they would eat contaminated food, unusual food combinations, and inedible combinations, relative to those with ID with other etiologies and those without ID. Interestingly, although individuals with PWS hold similar beliefs about the function and purpose of food compared to those without ID, they have problems converting this knowledge into safe and appropriate dietary practices.

2.6.6 Psychiatric Diagnoses

Pica has been observed in individuals with mental health disorders, such as dementia, obsessive-compulsive disorder, schizophrenia, and eating disorders in both the general and ID population.

2.6.6.1 Dementia

Several studies have documented eating abnormalities, including pica behaviour in older adults with dementia (Hope, Morris, & Fairburn, 1991; Ikeda, Brown, Holland, Fukuhara, & Hodges, 2002; Okuda, Harada, Mizutani & Hamanaka, 1998; Morris, Hope, & Fairburn 1989) although the prevalence is unclear. For example, Morris et al. (1989) found that among 33 individuals with dementia, 15% tried to eat inedible substances (i.e., feces, soap, flowers), and 15% ate inappropriate substances (i.e., uncooked food, pet food). They suggested that the failure to recognize objects (agnosia) or a loss of the *disgust* mechanism may account for the eating of inedible objects. In Hope et al.'s research, 22% of 85 individuals with dementia were reported to have chewed or swallowed non-food items. On the other hand, Ikeda et al. (2002) compared eating behaviours between three different subtypes of dementia: comparisons were made between frontal variant frontotemporal dementia (fv-FTD) (n=23), semantic dementia (n=25), and Alzheimer's disease (n=43) patients. Frontotemporal dementia refers to the progressive focal atrophy of frontal and anterior temporal lobes whereas semantic dementia refers solely to the atrophy of the temporal lobes (Ikeda et al., 2002). In contrast, the pattern of brain atrophy is distributed more broadly in dementia of the Alzheimer's type and includes atrophy of the frontal, temporal, and parietal areas. It was found that although pica was rare in all three groups, it was significantly more common in those with semantic dementia than in fv-FTD, or Alzheimer's disease. The authors postulate that the changes in eating behaviour and the increase in abnormal eating behaviour such as pica in those with dementia reflect damage in the ventral frontal lobe, temporal pole, and the amygdala. Previous research suggests that these areas are involved in taste, satiation, and Kluver-Bucy syndrome (syndrome characterized by hyper-oral behaviour). Collectively, these studies suggest that pica is associated with dementia and further study is required to replicate Ikeda's finding that those with semantic/temporal lobe dementia exhibit pica more frequently.

There are no known studies to date that have examined dementia and pica in persons with ID. This may be an important area of research to investigate as persons with Down's syndrome are at higher risk of developing Alzheimer's dementia compared to the general population and as such may manifest higher rates of pica.

2.6.6.2 Obsessive Compulsive Disorder

Pica has been considered by some to be part of the obsessive-compulsive spectrum disorders in which the ingestion of unusual substances leads to a decrease in anxiety or tension in the general population (Gundogar, Baspinar, & Eren, 2003; Solyom, Solyom, & Freeman, 1991; Zeitlin & Polivy, 1995). Luiselli (1996) believes that pica may be usefully conceptualized as compulsive behaviour in individuals with ID who exhibit extreme or persistent pica; however, no formal studies have examined this relationship.

2.6.6.3 Schizophrenia

Historically, it was suggested that pica was a vegetative symptom of psychosis (Kraepelin, 1907). In a recent study of repetitive behaviours associated with schizophorenia, it was found that 3% of 400 individuals with schizophrenia exhibited pica, and that they tended to have a chronic course of schizophrenia (Tracy, de Leon, Qureshi, McCann, McGrory, & Josiassen, 1996). Numerous case studies have also shown that schizophrenia is associated with pica (Beecroft, Bach, Tunstall, Howard, 1998; Federman, Kirsner, & Federman, 1997; Maiss, Naegel, Feess, Hahn, Raithel, 2005; Stone, Griffiths, Rastogi, Perry, & Cleland, 2003). A possible explanation of this relationship is that chronic schizophrenia results in deterioration in cognitive functioning due to brain atrophy (Beecroft et al., 1998; Stone et al., 2003). Alternatively, it has been suggested that frontotemporal dementia in young adults may be misdiagnosed as schizophrenia as the early signs are more similar to schizophrenia, but then progress to symptoms of dementia in the later stages (Stone et al., 2003). To a lesser extent, the literature suggests that pica is related to delusions or paranoid thinking (Dumaguing, Singh, Sethi, Devanand, 2003). With respect to the ID population, little is known regarding the relationship between schizophrenia and pica with the exception of 2 case studies reported by Dumaguing et al. (2003). They reported two individuals diagnosed with ID and schizophrenia early in life who subsequently developed pica late in life (i.e., age 40 and 76). These results contradict the general finding that pica is more common in younger individuals with ID and that it remits with age. However, these findings do support the notion that pica may be a symptom of chronic schizophrenia.

2.6.6.4 Eating Disorders

Other abnormal eating behaviours have been linked to pica. In the general population, people with anorexia or bulimia may attempt to ease hunger or reduce their caloric intake by eating nonfood substances to obtain a feeling of fullness (McLoughlin & Hassanyeh, 1990; Parry-Jones & Parry-Jones, 1994). However, in the ID population, rumination (the regurgitation of previously swallowed food) and hyperphagia (excessive eating) have been found to be significantly associated with pica (Danford & Huber, 1981) and are both hypothesized to serve a self-stimulatory function.

2.6.6.5 Addiction

Piazza et al. (1996) raised the issue of pica as self-medication, specifically highlighting the eating of cigarette butts for the physiological effects of nicotine, rather than other components of the cigarette (e.g., paper, filter). Thus, it may not just be the oral stimulation that maintains pica; the nicotine in the cigarettes serves to reinforce tobaccophagia.

2.6.7 Social Context

The environment, both socially and physically, may have an impact on the frequency of pica behaviour, but very little systematic research has been conducted in this area. The availability of structured activities (Tewari et al., 1995), the accessibility of pica objects, the amount of supervision, and social attention have been reported to possibly influence and maintain pica in case reports (Mace & Knight, 1986; Piazza, Fisher, Hanley, LeBlanc, Worsdell, Lindauer & Keeney, 1998). The rationale here is that fewer social interactions or meaningful activities may promote and/or maintain pica over time because the individual may be inclined to seek stimulation from mouthing/ingesting objects instead (Stiegler, 2005).

In reviewing the totality of the evidence concerning the risk factors, the strength of evidence in support of reported risk factors for pica must be considered. The risk factors most strongly supported by evidence are mineral deficiency followed by the consistent associations between profound severity of ID and gender with pica. There is moderate evidence that autism, dementia, and age play a role in the risk of pica. The limited number of studies on Prader-Willi syndrome, psychiatric disorders, and social factors prevents one from drawing firm conclusions about their importance as risk factors for pica. This review also demonstrates that some risk factors (e.g., deficits in expressive or receptive communication, self-care skills) have been neglected in past research.

2.7 Other Correlates of Pica

It is necessary to stress the importance of other medical and behavioural problems that often occur with pica which cause significant morbidity both for persons with ID and for their caregivers. Particular medications, sleep disturbance, stereotypic movement disorder, polydipsia, and aggressive behaviour often take place simultaneously with pica.

2.7.1 Medications

Medications, particularly psychotropics and anticonvulsants have been found to be significantly associated with persons with ID and pica (Danford & Huber; Decker, 1993; Witkowski, 1990). Neuroleptic medication, it is argued, may have a direct link with pica, due to “anti-dopaminergic effects” which may worsen pica behaviour (Singh, Ellis, Crews, & Singh, 1994). On the other hand, the higher rate of neuroleptic medication may reflect the treatment of choice for pica. These associations, however, are likely to be confounded by indication. That is, individuals with higher levels of cognitive impairment may be more likely to be prescribed these agents for other reasons besides pica (e.g., behavioural disturbance, epilepsy), whereas less severely cognitively impaired individuals would not use these. Therefore, the relationship between psychotropic and anticonvulsant medications and pica are questionable and requires a more appropriate study design to fully assess the reasons for using particular drugs among individuals with ID and pica.

2.7.2 Sleep Disturbance

Danford & Huber (1981) noted that individuals with ID and pica were often significantly more hyperactive during the day and awake at night compared to those without pica. They suggested that nocturnal activity was probably related to the fact that these individuals were searching for pica items.

2.7.3 Stereotypic Movement Disorder

Stereotypic movement disorder refers to motor behaviour that is repetitive and non-functional and includes hand waving, rocking, twirling objects, and also includes self-injurious behaviours such as heading banging, self-biting, and self-hitting (APA, 2000). Danford and Huber (1981), and Matson and Bamburg (1999) found a significant association between pica and stereotypic movement disorder. Further, Danford and Huber (1981) found that self injury was associated with a high incidence of pica. Future study of the relationship between self injury and pica is required. These findings, however, could be attributed to the person’s level of ID, as stereotypic movement disorder and self-injury are known to increase with the severity of ID (APA, 2000).

2.7.4 Polydipsia

Some researchers have proposed that pica represents a tendency to ingest indiscriminately. This is consistent with the finding of the co-occurrence of polydipsia, the ingestion of excessive quantities of fluid, with pica among institutionalized adults with ID (Dandford & Huber,1982; Deb, Bramble, Drybala, Boyle, & Bruce,1994; Rowland, 1999). Perhaps pica and polydipsia have the same behavioural and neuropsychological origins.

2.7.5 Aggression

Aggression in particular has been documented as a common behaviour in individuals who engage in pica. Researchers consistently note that individuals are either aggressive in their search for substances or they become aggressive or violent when they are interrupted or prevented from ingesting inedible objects (Bugle & Rubin, 1993; Danford et al., 1981; Danford & Huber, 1982; Hagopian & Adelinis, 2001; Piazza et al., 1996; Grewal & Fitzgerald, 2002; Jawed et al, 1993). Outbursts of anger and aggression towards others may also occur in individuals with ID because of abdominal pain and discomfort as a result of ingesting inedible items (Grewal & Fitzgerald, 2002). In contrast, one study noted that individuals with pica showed less aggressive behaviours as measured by a personality profile (Tewari et al., 1995). Despite numerous anecdotes in the literature reporting aggression in those with pica, there have been very few systematic studies of the relationship between pica and aggression and whether it is confounded by level of ID. The study of aggressive behaviour has both clinical and practical relevance for the treatment and management of pica.

2.7.6 Neurological Abnormalities Associated with Pica

It is not known why ID or other psychiatric disorders may be associated with pica. Frontal and temporal lobe abnormalities have been posited to be important in individuals with pica (Beecroft et al., 1998; Ikeda et al., 2002; Stones et al., 2003). The role of the temporal lobes in oral behaviour was first highlighted when it was discovered to be responsible for a set of behavioural changes known as Kluver-Bucy syndrome, that occurred in monkeys who sustained large temporal lobe lesions (Kluver & Bucy, 1937). These monkeys showed agitation, hypersexuality, and oral behaviours, including hyperphagia and pica. More recently, researchers have replicated this finding in individuals with dementia, and have demonstrated that those with semantic or predominantly temporal lobe dementia exhibit pica more often than other subtypes of dementia (Ikeda et al., 2002). Semantic dementia is predominantly characterized by abnormalities in language and as such is also referred to as a neurodegenerative language disorder. Semantic and language impairments have also been shown to be a prominent feature in those with ID and pica (Danford & Huber, 1981; Dudley et al., 1999). Although there are no known studies that have examined structural brain abnormalities in those with pica and ID, it may be inferred that pica results from damage to similar brain regions as those with semantic dementia. Therefore, it appears that pica may result from multiple causes of brain pathology (i.e., ID, dementia). More research is needed to clarify the specific brain regions and pathways that are impaired and involved in pica using modern brain imaging techniques.

In summary, pica is likely to be the expression of a number of different underlying mechanisms, both biological and psychological. It is important to investigate these various mechanisms in order to develop specific and effective treatments for pica.

2.8 Interventions

In this section, a review of the medical, nutritional, and behavioural interventions used to treat pica in persons with ID are presented. Burke and Smith (1999) have cautioned that most findings are based on studies using small sample sizes (case studies), short periods of time, and baiting (items are placed in the environment as pica targets). Further, intervention studies have been primarily conducted with children and therefore the effectiveness of interventions with adults with ID is not clear. Future research will need to focus on interventions for adults with ID and pica. The current trend is to perform functional analysis in order to discover the unique reinforcers that cause or maintain pica for a particular individual (Carr, 1994; McAdam, Sherman, Sheldon, Napolitano, 2004).

2.8.1 Medication

Pharmacologic therapy of pica has not been well documented in the literature. Treatment of pica with selective serotonin re-uptake inhibitors (SSRIs) has been suggested and has been shown to reduce pica intensity in two adults and one adolescent of normal intelligence with pica (Gundogar, Demir, & Eren, 2003). However, the use of thioridazine, an antipsychotic agent, was found to be ineffective in reducing pica in three adolescents with profound ID. These individuals displayed lower rates of pica during placebo phases versus the antipsychotic drug phase (Singh et al., 1994). Alternatively, the administration of a stimulant (i.e., methylphenidate), decreased pica rates in these individuals compared to the placebo phase.

2.8.2 Nutritional

A few studies have illustrated that nutritional supplements reduce the frequency of pica (Bugle & Rubin, 1993; Lofts et al., 1990; Pace & Toyer, 2000). Lofts et al. provided 100 mg of chelated zinc to 69 adults with ID residing in an institution who had zinc deficiency. Following the nutritional zinc supplement, the average number of pica incidents were reduced from 23 incidents to 4.3 incidents per individual. Bugle and Rubin (1993) showed that a dietary supplement, Vivonex, reduced the occurrence of coprophagia in two adults and one child with ID compared to their regular diet using an A-B-A design, though it did not extinguish it. Pace and Toyer (2000) found similar results in a child with ID and pica. However, none of the above studies showed that nutritional supplements eliminated the pica behaviour on their own.

2.8.3 Behavioural Treatments

The available literature presents numerous behavioural interventions for the treatment of pica; though the most effective approaches have not yet been identified. The interventions discussed below are presented from the least (ecological interventions, sensory interventions, discrimination training) to the most (response blocking, overcorrection, aversive substances, negative practice, self-protection devices, and physical restraint) intrusive interventions.

2.8.3.1 Ecological Interventions

Physical environment

Environmental controls that are often used to reduce pica behaviour include the removal and locking up objects from the environment that could be ingested by the individual (i.e., “pica proofing”) to help reduce the amount of time the individual must be supervised or restrained (Carter & Wheeler, 2004).

Social environment

Favell, McGimsey, and Schell (1982) found that adults with ID tended to engage in pica when they were alone or unoccupied and that by enriching their environment with toys the frequency of pica was reduced. Hirsch and Myles (1996) demonstrated that the availability of a “pica box”, containing safe edible and inedible items to a 10-year old child with autism decreased her pica behaviour. Similarly, a few studies have shown that increased stimulation, in the form of activities, social interaction, and attention for all ages can reduce pica (Mace & Knight, 1986; Piazza et al., 1998).

2.8.3.2 Oral Stimulation

This strategy is based on the hypothesis that pica is maintained by automatic reinforcement and that safer alternatives of oral stimulation (i.e., toys, food, drinks, and gum) are provided to compete with the person's pica. For example, Piazza, Hanley, Blakeley-Smith, and Kinsman (2000) trained a blind child to find alternative mouthing toys to replace his pica behaviour by attaching strings to his toys. A more specific approach is to provide stimuli that match the sensory properties of the inedible objects that the individual prefers to ingest. The provision of firm textured foods (e.g., carrot sticks, rice cakes) was more effective in reducing pica rates than soft textured foods (e.g., gelatin) in one adolescent and one child with ID who showed a propensity to ingest firm nonedible items (Piazza et al., 1998). However, more research is needed on the effect of oral stimulation in adults with ID.

2.8.3.3 Discrimination Training

Many have argued that a lack of discrimination of edible and inedible items is at the root of pica behaviour in those with ID (Johnson et al., 1994; Parry-Jones & Parry-Jones, 1994), though it is unlikely that teaching individuals to discriminate on its own will successfully treat pica over time due to the cognitive impairments of individuals with pica (Stiegler, 2005).

2.8.3.4 Response Blocking

Response blocking includes techniques that stop or prevent the person from engaging in pica, such as the use of verbal prompts, physical guidance, or physical removal. Hagopian and Adelinis (2001) found that response blocking in combination with redirection to alternative food choices was more effective at reducing pica and aggression than response blocking alone in an adult with ID.

2.8.3.5 Overcorrection

Overcorrection refers to correction of a behaviour through exaggerated practice and teaching (Bell & Stein, 1992). Oral hygiene routines, such as brushing teeth, hand and face washing, and tidying are overcorrection techniques that have been applied alone or in combination after a person displays pica behaviour and has been shown to reduce pica rates in adults and adolescents with ID (Foxx & Martin, 1975; Singh & Winton, 1985).

2.8.3.6 Aversive Substances

Aversive substances, such as water mist, lemon juice, and ammonia are sometimes used as a punishment and are either squirted at the person's face or mouth, or smelled by the person (in the case of ammonia) (Paisey & Whitney, 1989; Rojahn, McGonigle, Curcio, & Dixon, 1987). Rojahn et al.(1980) demonstrated that water mist compared to ammonia was more effective at reducing pica in an adolescent with autism.

2.8.3.7 Negative Practice

Negative practice is an aversive approach that is based on the principle that repetition of a behaviour would eventually become aversive to the individual who engages in the behaviour. For example, Duker and Nielen (1993) used negative practice in which each time the adult with ID engaged in pica, the staff would press the person's hand containing the nonedible item to her lips without allowing her to bite on the item for two minutes. Following numerous repetitions of this negative practice procedure, pica rates were reduced but not completely eliminated in the individual.

2.8.3.8 Self-Protection Devices

When pica is severe and life-threatening or dangerous objects (e.g., nails, glass) are sought, self-protective devices that prevent the person from engaging in pica are used (Bell & Stein, 1992); these include mechanical restraints (i.e., mesh bags or hoods, jackets that restrain the person's arms and hands, and fencing masks or helmets with a face shield that restrict access to the person's mouth). Ausman, Ball, and Alexander (1974) reported a reduction in pica behaviour in an adolescent with ID and pica using a time-out helmet for 15 minutes every time he engaged in pica combined with food rewards when his pica did not occur. Similarly, Rojahn, Schroeder, and Mulick (1980) found that the use of camisole and fencing masks for two hours every weekday among three adults with ID reduced pica, although their work and social interactions decreased. Le Blanc, Piazza, and Krug (1997) reported the case of a child who was able to ingest parts of the restraint equipment and suggest that pica could be reduced just as well without using self-protective devices.

2.8.3.9 Physical Restraint

Similar to self-protective devices, physical restraint techniques are used to restrict the person's opportunities to engage in pica. Studies have suggested that brief physical restraint in the form of restraining an individual's arms at the side of the person's body for 10 seconds is effective at reducing pica in adults and adolescents (Nash, Broome, & Stone, 1987; Winton & Singh, 1983).

2.9 Resource Utilization

In general, adults with ID have a distinct set of support needs because of their functional impairments, and vulnerability to medical diseases and emotional/behavioural disorders.

However, it is important to recognize that there are particular subgroups of individuals with ID who are more or less resource intensive than others. Although it is well known that individuals with ID have a higher prevalence of comorbid psychiatric disorders and challenging behaviours, there is a dearth of literature in the area of resource use among this subpopulation, and in particular among those with pica. A study by Lin, Yen, Li, and Wu (2005) support the notion that individuals with comorbid ID and psychiatric disorders have poorer health status and consume more medical services (outpatient care, inpatient care, and emergency services) than individuals with ID without psychiatric disorders. Therefore, further investigation is required to assess the significance of pica with respect to staff resources and health care utilization in order for service providers to better understand their support needs. This is an important first step in identifying distinct resource groups within the ID population that have more complex needs so that service providers can allocate funding based on individual characteristics rather than providing global program funding to persons with ID.

2.10 General Limitations of the Existing Literature

While some of the factors that might contribute to pica are broadly understood, there is a very limited understanding as to the mechanisms involved and how they interact. Only one study to date has demonstrated that low levels of iron, zinc, and profound level of ID contribute to pica using multivariate statistical techniques (Swift et al., 1999). However, Swift et al. (1999) did not examine all possible risk factors for pica and their possible interactions in the model. As pointed out by Ali (2001), neurochemical and neurological abnormalities will also need to be considered as potential risk factors for pica. Longitudinal studies are also lacking in the literature and are required to determine the onset and course of pica among individuals with ID, and to inform on best practices (e.g., effective interventions) for pica. It is also not clear in the literature what are the service needs of adults with pica with respect to staff supervision and health care utilization. The present thesis will attempt to explain the occurrence of pica and determine whether it plays a significant role in resource consumption. Finally, this research will investigate the social-quality of life of persons with pica. These findings will have implications for determining the necessary supports required by persons with ID and pica.

3.0 Study Objectives and Research Questions

3.1 Purpose of the Study

To date, much of the knowledge about pica is derived from institutional samples and has focused on the prevalence and behaviour management of pica giving little attention to its etiology and impact on the quality of life of individuals who engage in the behaviour. With the emphasis on community integration for individuals with ID, reflected by the closure of institutions in Ontario (MCSS, 2006), persons with ID are increasingly being supported in the community, where staff and support networks may not have adequate knowledge recognizing and managing pica. Furthermore, numerous anecdotes in the literature report that individuals with pica require a high degree of supervision and have limited social and recreational opportunities but no known empirical studies have examined this.

The purpose of this study is mainly to compare persons with ID who engage in pica to those who do not. Secondary data sources were used to assess the prevalence, risk factors, social consequences, and service patterns of persons exhibiting pica. Finally, to gain insight into the support needs of adults with pica, two focus groups were conducted with front-line staff in the community and institution to examine the needs, struggles, and types of support required.

The objective of this study is to answer the following research questions:

1. What is the prevalence of pica among individuals with ID living in the community versus those living in institutional settings?
2. What demographic, functional, and clinical characteristics, and challenging behaviours are associated with pica?
3. What are the medical characteristics of pica?

In addition, in order to extend the body of knowledge in this area, this investigation will attempt to answer some previously unexamined questions as follows:

1. What factors explain the occurrence of pica?
2. What interventions and treatments are received by those with pica compared to those without pica?
3. What impact does pica have on explaining resource utilization (i.e., staff ratings of one-to-one supervision)?
4. What are the social characteristics of pica?
5. What are the perspectives of staff that support persons with ID and pica in community and institutional settings?

In the first phase of this research, facility and community data sets will be used to inform on the above research questions. The second phase of this research is based on the qualitative analysis of focus groups with direct-care staff. These two approaches were used to provide a more integrated and complete picture of the characteristics and needs of persons with ID and pica.

4.0 Quantitative Methods

4.1 Samples

Data for the proposed study were drawn from four pilot studies using the inter*RAI* ID assessment instrument. Following is a brief description of each sample. Overall, 1, 430 adults with ID were assessed using the inter*RAI* ID.

4.1.1 ID Facility Sample

4.1.1.1 Ontario Ministry of Community and Social Services inter*RAI* ID 3.0

The entire population (N=1010) of Ontario's three remaining facilities for individuals with ID (i.e., Huronia, Rideau, Southwestern) were assessed between April, 2005 and June, 2005 using the inter*RAI* ID version 3.0 (Appendix A). In addition, each resident was assessed with respect to the amount of one-to-one care or supervision they currently received and were expected to need upon community placement, using the inter*RAI* ID Supplement (Appendix B). This research effort was contracted by the Ministry of Community and Social Services (MCSS) with the University of Waterloo's **ideas** *for Health* research team in 2005 and involved the assessment of all residents in Ontario's facilities in order to better understand their needs and characteristics. These three facilities are the only ones still in operation today compared to 20 in 1970; however, they are scheduled to close by March 31, 2009 as part of the final stages of the deinstitutionalization movement in Ontario (Radford & Park, 2003). Information obtained from the inter*RAI* ID will be used by the MCSS to aid in the community integration of these individuals over the next four years. The Huronia Regional Centre is a residential facility that provides support to adults with ID in a series of residences in the town of Orillia. A total of 336 individuals were assessed. Rideau Regional Centre in

Smith Falls, Ontario is a residence for 421 persons with ID. The Southwest Regional Centre is a Blenheim (Chatham-Kent) area facility that is home to 250 residents who were assessed. Residential facility information was missing for three individuals.

4.1.2 ID Community Samples

The inter*RAI* ID has been pilot-tested in various community settings in Ontario and Nova Scotia. A total of 420 community-dwelling adults with ID have been assessed. It is important to note that these samples were convenience samples and therefore may not be generalizable to all community-dwelling individuals with ID.

4.1.2.1 Nova Scotia Department of Community Services (NS-DCS) inter*RAI* ID 2.0

The first sample consists of 209 community-dwelling adults with ID supported by the Nova Scotia Department of Community Services (NS-DCS) and were assessed between November 2004 and April 2005 using the inter*RAI* ID version 2.0.

4.1.2.2 Ontario Rate of Clinical Change Study inter*RAI* ID 2.0

The second sample consists of 118 adults with ID assessed as part of a longitudinal study examining the rate of clinical change over the course of one year. One hundred and eighteen adults with ID assessed at time 1 of the study (between November 2004 and February 2005) using the inter*RAI* ID version 2.0 will be included in the present study. The sample is comprised of 81 adults with ID from the Woodstock Developmental Disability Services (WDDS); 20 adults with ID from Kitchener-Waterloo Habilitation Services; and 17 adults with ID from the Cambridge Association for the Mentally Handicapped (CAMH). These three agencies are non-profit and provide a wide range of services, including residential, vocational, respite, life skills training, and recreation and leisure programs for adults with ID.

4.1.2.3 Ontario inter*RAI* ID 1.0

The third sample consists of 124 individuals with ID who were assessed as part of the original pilot study of the inter*RAI* ID. Staff in three community agencies in southwestern Ontario assessed a subset of their clients between May 2003 and October 2004, using the inter*RAI* ID version 1.0. The sample consisted of 58 adults with ID from Kitchener-Waterloo Habilitation Services (Kitchener, Ontario); 57 adults with ID from Cambridge Association for the Mentally Handicapped (Cambridge, Ontario); and 10 adults with ID supported by the Mental Health Services for Adults with Dual Diagnoses team from St. Joseph's Health Care Centre (Hamilton, Ontario). Of these 124 individuals assessed, 31 were re-assessed in the Ontario rate of clinical change study previously mentioned above. Therefore, only 93 individuals from this study were included in the overall community sample to avoid duplication.

4.2 Measures

4.2.1 interRAI Intellectual Disability Instrument (interRAI ID)

inter*RAI* (www.interrai.org) is a non-profit collaborative consisting of approximately 50 researchers and clinicians from 26 countries committed to improving the quality and services offered to individuals in the health and social system through standardized health assessment. inter*RAI* has developed assessment tools for use in various health and social service settings, including long term care (inter*RAI* LTCF), home care (inter*RAI* HC), acute care (inter*RAI* AC), post-acute care (inter*RAI* PAC), in-patient psychiatry (RAI-MH/inter*RAI* MH), community mental health (inter*RAI* CMH), and palliative care (inter*RAI* PC). More recently, an assessment system specifically designed to assess the needs of adults with an intellectual disability (inter*RAI* ID) was developed.

Data collected using the inter*RAI* Intellectual Disability (inter*RAI* ID) will inform on the research questions regarding facility and community-dwelling adults with ID for this study. Following is a description of the inter*RAI* ID and its psychometric properties.

The inter*RAI* for Intellectual Disability (inter*RAI* ID) was developed to assess "the strengths, preferences, and needs of adults with ID" across all levels of intellectual impairment in various support settings (Martin, 2004). The inter*RAI* ID is originally based on items from other inter*RAI* instruments for inpatient psychiatry, nursing homes, and home care, and thus is compatible with other inter*RAI* instruments. The development of the domain areas and items of the instrument involved a comprehensive literature review, feedback from front-line workers and clinicians in the field of ID, and the examination of its psychometric properties. The overall goal of the instrument is to screen for a variety of potential problems in the ID population using the minimum number of items. In addition, information collected from the inter*RAI* ID can be used to create individualized life plans—an action plan for assisting individuals with ID to meet their needs, and to express and move toward their lifelong goals and desires. Like other inter*RAI* instruments, the inter*RAI* ID gathers data on the functional status of its population and uses clear response categories, standardized definitions, inquiry over a relevant time period (i.e., over last 3 days), and multiple information sources (i.e., the person, family members, direct-care staff, and relevant documentation).

The inter*RAI* ID (Appendix A) version 1.0 is a 391-item instrument that evaluates functioning in 18 domain areas: personal information, intake information, health service history, cognition, communication, physical functioning, physical health, medications, medical and psychiatric diagnoses, skin condition, oral and nutritional status, mood, life events, behaviour, psychosocial well-being and social supports, occupation (i.e., education, vocation, and recreation), prevention and intervention, and home environment. The inter*RAI* ID also generates nine subscales that measure cognition (CPS), self-care (ADL-Hierarchy), instrumental activities of daily living (IADL), pain (Pain Scale), instability of health (CHESS), depression (DRS), aggression (ABS), psychosis (PSS), and negative symptoms (NSS).

The psychometric properties of the inter*RAI* ID have been reported by Martin (2004). One hundred and sixty persons with an intellectual disability, from mild to profound levels of ID were assessed. Initial findings indicate that the internal consistencies of the embedded clinical subscales are good. The internal consistency of the subscales (i.e., ADL-SF, DRS, PSS, NSS, and ABS) was established by computing Cronbach's alpha coefficient values for each. It should be noted that the internal consistency of the embedded cognitive performance scale (CPS) could not be calculated because it is based on a predictive algorithm rather than a summated scale (Martin, 2004). Among the 5 remaining subscales there was some variation in alpha values obtained, ranging from 0.93 for the ADL short-from scale (ADL-SF) to 0.71 for the psychotic symptoms scale (PSS). Despite this variation, all alpha values exceeded the industry standard of 0.70.

There is also evidence of the criterion validity for the subscales in the inter*RAI* ID. Pearson product-moment correlation coefficients were calculated to measure the associations between the inter*RAI* subscales and a single item on expressive communication to the corresponding subscales from two established gold standard instruments: the Reiss Screen for Maladaptive Behaviour (RSMB), a measure of psychopathology, and the Dementia Questionnaire for Persons with Mental Retardation (DMR), a measure of cognition in those with ID. Correlations between the inter*RAI* ID subscales and the corresponding gold standard subscales ranged from 0.41 to 0.93 (Martin, 2004). Excellent criterion validity was observed between the ADL-SF and the DMR Practical Skills Subscale (r=0.93), CPS and DMR Sum of Cognitive Scores (r=0.83), and expressive communication and the DMR Speech Subscale (r=0.80). Moderate relationships were found between the ABS and the RSMB Aggression Scale (r=0.60), as well as the DRS and the RSMB Depression scale behaviour (r=0.65), and the Depression scale physical (r=0.50). Modest associations were observed between the PSS and RSMB Psychosis Scale (r=0.45) and the NSS and the RSMB Avoidant Disorder Scale (r=0.41). Despite the substantial variation in correlations obtained, the inter*RAI* ID subscales were all significantly (p<.0001) related to the gold standard subscales and thus the inter*RAI* ID could presumably replace these stand-alone gold standard assessments and reduce the staff burden of filling out redundant assessments (Martin, 2004).

Although the purpose of the pilot study was not to provide evidence on the convergent validity of the inter*RAI* ID, some important associations were found between key variables of interest that have been identified in the literature. For example, level of ID was shown to be positively correlated to CPS score (r = 0.79, p <.0001) demonstrating that the CPS score is able to indicate ID severity (Martin, 2004). In addition, level of ID was significantly associated with functional status as measured by the ADL-SF (r=0.69), and expressive communication (r=0.76). Overall, it was found that increasing levels of ID were associated with greater functional impairment.

Since the inter*RAI* ID is currently in the piloting phase of development, the inter-rater reliability, and test-retest reliability of the inter*RAI* ID have not yet been established. Further testing of the instrument’s psychometric properties are required and are currently underway.

It should be note that the reliability of the items contained within the inter*RAI* ID have been extensively tested in other instruments and settings, including the Minimum Data Set (MDS) for long term care homes, and the inter*RAI* Mental Health system (MH) for in-patient psychiatry in which persons with ID are also found (Hawes, Morris, Phillips, Fries, Murphy, Mor, 1997; Hawes, Morris, Phillips, Mor, Fries, and Nonemaker, 1995; Hirdes et al, 2002). The inter*RAI* ID has gone through minor modifications and has been further refined into version 2.0 and 3.0 (See Appendix A for version 3.0), although the domain areas and the bulk of the items are identical to version 1.0. The pilot studies using these versions will also be included in the present study for analyses.

4.2.2 interRAI ID Supplement: Staff Ratings of Support Needs

In addition to the inter*RAI* ID measure, each resident in the facility population was also assessed by both a staff and site coordinator regarding: a) the amount of one-to-one direct care or supervision received on the most intensive day in the last three days (scores are based on a categorical scale of 0 to 5, with 0 indicating no hours and 5 indicating between 16-24 hours of supervision); and b) the expected change in need for one-to-one direct care or supervision after community placement (no change, expected increase, or expected decline) using a supplemental form (See Appendix B). The psychometric properties of this supplemental form have not been investigated.

4.3 Study Variables

Following is a detailed description of the study variables that were used to carry out the above analyses. The variables of interest for this study and their coding are presented in Appendix C.

4.3.1 Dependent Variable

The primary outcome of interest is the presence of pica. For the purpose of this study, pica is defined as “the ingestion of non-food items such as soap, dirt, and feces” (Martin, 2004). Pica was rated for its frequency, distinguishing those in which pica never occurred, those that exhibited pica in the past but not in the last three days, 1-2 of the last three days, and in the last 3 days in the inter*RAI* ID versions 2.0 and 3.0. The three day time frame is used in the inter*RAI* ID to capture clinically relevant issues that are of an observable and immediate concern for support planning versus those that have not occurred in the last three days. Behaviours such as pica, that have not occurred in the last three days but are known to be present, however, are still recognized as management issue but not to the same degree. The presence of pica was rated differently in the inter*RAI* ID 1.0 such that pica was either rated as not occurring or occurring in the last 30 days.

4.3.2 Independent Variables

Demographic Variables

The demographic variables such as age and gender were derived from the identification section of the inter*RAI* ID 1.0, 2.0, and 3.0. Age was coded as a continuous as well as an ordinal variable. Further, age at which the person left home, number of years (lifetime) spent in an institutional setting, and current length of stay in the institution were also examined. If the above responses were unknown or if the question did not apply, these values were set to missing. The cause of ID or specific ID syndrome was compared between those with and without pica. Of particular interest were the syndromes of autism, and Prader-Willi syndrome.

Cognitive Function

The severity of cognitive impairment was measured in two ways. First, the severity of intellectual disability was derived from the documented severity of intellectual disability item. The severity of ID item utilizes the DSM-IV-TR criteria that classifies severity by IQ for persons with ID.

The Cognitive Performance Scale (CPS) was used as an additional measure for severity of ID because of the fact that the severity of ID among individuals with ID is commonly unknown or undocumented (Martin, 2004). The CPS indicates an individual's level of cognitive impairment and is comprised of four items: short-term memory, daily decision-making, expression, and self-performance in eating. Scores range from 0 (intact) to 6 (very severe cognitive impairment) with 0-2 indicative of mild impairment and scores greater than 5 indicative of severe cognitive impairment. Initially, the CPS was developed to screen the cognitive status in persons residing in nursing homes and has been shown to be highly correlated to the Mini-Mental State Examination (MMSE) in a nursing home population (0.86, $p<0.001$)(Hartmaier, Sloane, Guess, Koch, Mitchell, Phillips, 1995). Within the field of ID, the CPS has been validated against the DMR Sum of Cognitive Scores ($r=0.83$, $p<0.001$) among community-dwelling adults with ID (Martin, 2004). Moreover, the CPS has been shown to be highly correlated with severity of ID ($r=0.79$, $p<.001$) (Martin, 2004).

Communication

Individuals with and without pica were compared with regard to their method of communication (i.e., verbal vs. non-verbal), their ability to communicate (self expression), and their ability to comprehend information (comprehension).

Self-Care Skills

The functional status of individuals with and without pica was compared with regard to mobility (i.e., walking), and the use of a wheelchair. Two scales that have been developed to measure a person's level of functioning in day-to-day life were also used for analyses and included: Activities of Daily Living (ADL) Hierarchy Scale and the Instrumental Activities of Daily Living (IADL).

The ADL-Hierarchy Scale is a hierarchical scale that categorizes ADLs according to stages at which they can no longer be performed from early loss (e.g., hygiene) to late loss (e.g., eating) ADLs. This scale is generated from 4 items: personal hygiene, toilet use, walking, and eating with a resulting hierarchical scale ranging from 0 (independent) to 6 (total dependence on others). It has been found to be highly correlated to the Practical Skills subscale in the DMR among adults with ID living in the community (Martin, 2004).

The Instrumental Activities of Daily Living (IADL) Performance Scale is an additive scale and encompasses 8 items in the inter*RAI* ID and includes: meal preparation, ordinary housework, managing finances, managing medications, phone use, shopping, transportation, and work. Each IADL task is coded on a 6-point scale where 0 indicates independence and 6 indicates total dependence. The IADL summary score ranges from 0 to 48, with higher scores indicating that a person is more dependent on others for IADL tasks.

Behavioural Characteristics

A number of challenging behaviours are associated with pica and were examined. These included: wandering, verbal abuse, physical abuse, socially inappropriate or disruptive behaviour, inappropriate public sexual behaviour or public disrobing, self-injurious behaviour, destructive behaviour, outburst of anger, resists care, rumination, and polydipsia.

Psychiatric Diagnosis and Psychiatric symptoms

The documented provisional diagnoses (dementia, schizophrenia or psychosis, mood, and anxiety disorders) was compared between those with and without pica. In addition, psychiatric symptomatology was examined between the groups using select embedded scales for depression and aggression. Following is a description of each scale.

The Depression Rating Scale (DRS) screens for depression and is one of the best studied scales among the inter*RAI* series of subscales. It is a summated scale of 7 items (negative statements, persistent anger, unrealistic fears, repetitive health complaints, repetitive anxious complaints, sad/pained/worried facial expression, crying or tearfulness) with scores ranging from 0 to 14. Scores of 3 or greater have been shown to be sensitive in indicating major depression and minor depression (e.g., dysthymia, dementia with depression) (Burrows, Morris, Simon, Hirdes, Phillips, 2000). The DRS has been validated against the Hamilton Depression Rating Scale (r=0.70), the Cornell Scale for Depression (r=0.69), and psychiatric diagnosis (sensitivity=91%, specificity=69%) in a nursing home population. The DRS has also demonstrated close correspondence with the subscales of physical and behavioural depression in the RSMB among community-dwelling adults with ID (r=0.50 and 0.65, respectively) (Martin, 2004). The convergent validity of the DRS has also been established by Hirdes, Smith, Rabinowitz, Yamauchi, Perez, Curtin-Telegdi, Prendergast, Morris, Ikegami, Phillips, and Fries (2002) in psychiatric patients. They confirmed the link between depression and suicidality using the DRS. The DRS was categorized into no signs of depression (score of 0-2) and possible signs of depression (scores of 3 or greater).

The Aggressive Behaviour Scale (ABS) is an additive scale that measures aggression and is generated by four items: verbal abuse, physical abuse, socially inappropriate or aggressive behaviour, and resisting care. Scores range from 0 to 12, with higher scores indicating greater severity of aggression. The psychometric properties of the ABS have only been examined in a sample of community-dwelling adults with ID; it has been found to be highly correlated with the aggression subscale in the RSMB ($r=0.60$, $p < 0.001$) (Martin, 2004). The ABS was categorized into three levels of severity: none (score of 0), mild to moderate aggression (scores between 1 and 4), and severe aggression (scores of 5 or greater).

Social Characteristics

To better understand the social consequences of pica a number of social variables were compared between those with and without pica, including strong and supportive relationship with family, social contact (visit with long-standing social relation or family member, other interaction with long-standing social relation or family member, overnight stay of 1 or more nights at home of family member or long-standing social relation), interpersonal conflict (conflict with or repeated criticism of family or friends, conflict with or repeated criticism of other care recipients or staff, family or close friends are persistently hostile toward person), sense of involvement (at ease interacting with others, at ease doing planned or structured activities, pursues involvement in activities of residential setting or community), and participation in social activities of long-standing interest. Lastly, involvement in different types of activities regardless of the person’s preference was determined and compared between the two groups (See Appendix C for the list of activities).

Medical Characteristics

The *Changes in Health, End-stage disease, and Signs and Symptoms* (CHESS) scale was used to evaluate the medical status of individuals with pica; it measures instability in health and predicts mortality (Hirdes, Frijters, Teare, 2003). Its main objective is to identify individuals who are a risk for decline in functioning. The CHESS scale is created from the following items: decline in two domains in the last 90 days (cognition, ADL), the presence of 5 of the following health problems (vomiting, dehydration, decrease in the amount of food/fluid usually consumed, weight loss, shortness of breath, and edema), and the presence of an end-stage disease. The end-stage disease item is not available in the inter*RAI* ID and thus scores for the CHESS range from 0 (no health instability) to 4 (highest level of health instability) instead of a 6-point scale in other inter*RAI* instruments. Hirdes et al. (2003) found that higher levels on the CHESS were associated with reduction in survival over time. Studies are needed to assess the validity of the CHESS in other populations, such as the ID population. For the purposes of analysis, the CHESS scale was collapsed into a dichotomous variable: health stability (score of 0) versus any presence of health instability (score of 1 or greater).

There is considerable evidence in the literature that pica results in significant morbidity. Therefore, the potential health consequences of pica were investigated. Specifically, gastrointestinal symptoms were examined, including the frequency of acid reflux, constipation, diarrhea, increase/decrease in normal appetite, nausea, vomiting, and the diagnosis of gastrointestinal disorder. The presence of iron deficiency, anemia, and low zinc levels was of interest as well, as these are known correlates of pica. Information on the diagnosis of gastrointestinal disease and mineral deficiency was derived from the documented medical diagnoses section. These are open-ended questions in the inter*RAI* ID.

Interventions

The patterns of interventions offered/received and the use of psychotropic medication among adults with and without pica were compared. Analysis included the receipt of formal services (e.g., social skills training, behaviour management, sensory stimulation, etc.), and the type of psychotropic medications prescribed. Classes of psychotropic medication were coded as binary variables.

Supervision

Information regarding the amount of supervision required to support individuals with pica was derived from the inter*RAI* ID Supplement and has been described elsewhere in this thesis. The staff’s ratings were used instead of the facility coordinator’s ratings for determining the supervision intensity of persons with pica relative to those without pica for two reasons. First, the direct-care staff had taken the time to observe the person and collect information from multiple sources to complete the inter*RAI* ID assessment whereas the facility coordinators did not participate in data collection. Secondly, although the facility coordinators had had front-line experience with the residents in the past the direct-care staff had more recent contact and greater familiarity with the person at the time of the assessment. Thus, the direct-care staff had more comprehensive knowledge of the person’s support needs and it was therefore decided that their clinical judgement was more reasonable to use. Therefore, staff ratings of the current and expected amount of one-to-one supervision upon community placement was compared between those with and without pica.

4.4 Statistical Analyses

Two data sets were created and used: 1) inter*RAI* ID facility, 2) inter*RAI* ID community. All statistical analyses were performed using SAS software version 9.1. A significance level of 0.05 was chosen for all analyses.

4.4.1 Data Cleaning

Prior to performing analyses, a series of data checks were performed to ensure the quality of the data. First, the uniqueness of the identification numbers were screened using PROC FREQ to confirm that there were no duplicates. To identify invalid categorical values (e.g., gender), PROC FREQ was used to list all the unique values for the variables and their frequencies, while PROC MEANS, PROC TABULATE, and PROC UNIVARIATE procedures were used to look for invalid continuous values (e.g., age). Once these invalid values were identified, they were either corrected or simply recoded as missing values. In addition, continuous variables were plotted to check for their distribution and transformations were employed in order to meet the assumptions of the analysis to be performed or the variable was recoded as a categorical variable. Following the cleaning of the data, a number of research questions were explored using univariate, bivariate, and multivariate techniques.

4.4.2 Univariate Analyses

Univariate analyses were carried out on select demographic variables to describe each sample. Categorical variables (e.g., gender) are described using percentage distributions while continuous variables (e.g., age) are described by reporting their mean and standard deviation. In addition, univariate analysis was used to provide estimates of the prevalence of pica in each setting. The prevalence of pica was calculated in two ways. First, the overall presence of any pica was calculated in both settings. Secondly, the prevalence rate of pica observed in the last 3 days and those who had a recent history of pica (i.e., present but not exhibited in the last 3 days) was calculated separately for those with ID residing in the facilities.

4.4.3 Bivariate Analyses

To understand the characteristics and unique needs of persons with pica, comparisons were made between adults with and without pica for select demographic characteristics, functional characteristics, communication characteristics, clinical characteristics (psychiatric diagnoses, depression, and aggression), challenging behaviours, medical characteristics (mineral deficiency, and gastrointestinal symptoms), social characteristics, involvement in recreational activities, types of interventions, and the current and expected amount of one-to-one supervision. Cross tabulations were performed to compare individuals with pica versus those without pica. Chi-squared (X^2) tests were used to evaluate the significant differences between categorical variables, and t-tests were employed for continuous variables.

4.4.4 Multivariate Analyses

A set of correlates for pica have been identified in the literature and include demographic (i.e., age, sex, autism and Prader-Willi syndrome), functional (severity of ID/cognitive impairment, self-care skills), communicative (non-verbal), clinical (i.e., psychopathology), and medical characteristics (i.e., mineral deficiencies). The relationship between pica and these correlates were examined using binary logistic regression in order to develop a model to predict pica behaviour among institutionalized adults with ID. Pica was the outcome, and all of the above candidate correlate variables that were significant at the bivariate level were entered into the model to determine the multivariate odds ratio and corresponding p-values. This technique was used instead of relying on automated stepwise techniques which can produce statistical significant findings that are not always clinically relevant. Independent variables that did not significantly predict pica ($p > .05$) were removed from the logistic regression model one at a time; the final multivariate model only included those variables significant at $p <.05$.

Second, multiple binary logistic regressions were used to determine if pica predicted various types of social consequences. A separate regression analysis was undertaken for each type of social consequence (absence of strong and supportive family, absence of social contact, absence of participation in social activities of long-standing interest, and lack of activity involvement). Here the logistic regressions modeled the probability of *not* having these characteristics. The goal is to evaluate the importance of pica as a predictor for each selected social domain, after controlling for a number of demographic, functional, and clinical factors. The presence of pica was evaluated in combination with other confounding factors, including age, gender, length of stay, cognitive functioning, activities of daily living, autism, and aggression. For all analyses, various combinations of the independent variables with pica were assessed manually to develop each final model. Only confounders that were significantly associated with each type of social consequence were included in the final model with pica.

Third, binary logistic regression analysis was undertaken to assess the significance of pica in predicting the amount of one-to-one supervision received over a 24-hour period using the staff ratings from the inter*RAI* ID Supplement. The logistic regression modeled the probability of a person receiving 8 hours or more of supervision versus 8 hours or less of supervision while controlling for the influence of potential confounders (age, gender, aggression, self-injury, cognitive functioning, and activities of daily living). Confounders that did not reach significance were removed from the final logistic regression model.

5.0 Results

The results of the statistical analyses are presented independently for community and facility-based settings. The community results are confined to descriptive analysis due to the small sample of persons with pica. The facility results include descriptive as well as bivariate results, followed by logistic regression modelling on factors that predict pica, and the impact of pica on various aspects of social functioning and staff supervision. Discussion of the results, recommendations for future research, as well as implications for clinical practice and policy are found in Sections 6.0 and 7.0.

5.1 Sample Characteristics

5.1.1 Community Sample Characteristics

Descriptive statistics for the community sample are shown in Table 1. The mean age for the whole sample was 43 years, with the majority of persons aged between 18 to 44 years. Over half of the sample was male. The most frequent diagnosis of ID was mental retardation, followed by down’s syndrome, other nature of ID, and autism. The majority of persons either had an undocumented severity of ID or borderline/mild ID.

Table 1 Community Sample Characteristics (n=420)

Characteristics	% (n)
Age Category	
18-44 years	57.2 (237)
45-54 years	22.5 (93)
55+ years	20.3 (84)
Male	54.5 (224)
Nature of ID	
Mental Retardation	79.8 (332)
Down’s syndrome	11.5 (48)
Autism	4.1 (17)
Other	4.6 (19)
Severity of ID	
Borderline/Mild	30.0 (124)
Moderate	16.7 (69)
Severe	10.6 (44)
Profound	2.4 (10)
Undocumented	40.3 (167)

Characteristics	Mean (SD)
Age	43.3 (14.1)
Length of stay in agency	13.1 (9.3)

5.1.2 Facility Sample Characteristics

The original facility sample size was changed as two persons residing in the facility were found not to have an ID. The decision was made to remove these individuals and therefore the total facility sample for this study is 1,008.

Descriptive statistics for the facility sample are presented in Table 2. Persons residing in the three facilities were, on average, 52 years of age. The majority of persons were male and had unspecified mental retardation or other cause of ID. In terms of severity of ID, half of persons had profound ID while 21.1% had an undocumented severity of ID, and 17.0%

had severe ID; few persons had borderline, mild, or moderate ID. On average, persons with ID left their family home at 9 years of age, and had resided in an institutional setting for 41.6 years.

Table 2 Facility Sample Characteristics (n=1008)

Characteristics	**% (n)**
Age Category	
18-44 years	25.6 (251)
45-54 years	45.3 (444)
55+ years	29.1 (286)
Male	62.0 (622)
Nature of ID	
Mental Retardation (unspecified)	34.5 (348)
Down's syndrome	8.8 (89)
Autism	3.5 (35)
Prader-Willi Syndrome	0.0 (0)
Other	53.2 (536)
Severity of ID	
Borderline	0.4 (4)
Mild	2.5 (25)
Moderate	8.2 (82)
Severe	17.0 (170)
Profound	50.8 (510)
Undocumented	21.1 (212)

Characteristics	**Mean (SD)**
Age	51.6 (9.4)
Age at which person left family home	9.3 (7.7)
Number of years (lifetime) spent in an institution	41.6 (10.3)
Length of stay in current institution (years)	38.9 (10.7)

5.2 Prevalence of Pica in Community and Facility Settings

The prevalence of pica among adults with ID residing in community and facility settings is presented in Table 3. Overall, 3.3% of adults with ID residing in the community were found to exhibit pica. In contrast, 22.0% of adults with ID residing in Ontario's three remaining facilities were known to have engaged in pica behaviour. Of those who were identified as having pica in the facilities, approximately one third had exhibited pica during the assessment time period (in the last 3 days) while close to two thirds had a recent history of pica but had not exhibited pica during the assessment period time. Therefore, the majority of persons with pica residing in the facilities did not display pica during the assessment time period.

Table 3 Prevalence of Pica by Setting

Setting	% (n)
Community	
Overall	3.3 (14)
Facility	
Overall	22.0 (220)
Present in the last 3 days	35.5 (78)
Present, but not exhibited in the last 3 days	64.5 (142)

5.3 Factors Associated with Pica in Facility Settings

5.3.1 Bivariate Analyses

5.3.1.1 Personal Characteristics by Presence of Pica

In this section, results are presented for adults with and without pica residing in Ontario's three remaining facilities. Table 4 provides a summary of the demographic characteristics of persons with and without pica.

Comparisons between individuals with and without pica indicated that individuals with pica were more likely to: be younger (t =3.01, p=.003), be male; leave their family home (be placed out of their family home) earlier; have a diagnosis of autism; and have an undocumented severity of ID. On the other hand, individuals with pica were less likely to: be 55 years or older, have a diagnosis of Down's syndrome; and have mild or moderate levels of ID compared to those without pica. It is important to note that no individuals with or without pica had Prader-Willi syndrome, a syndrome known to be associated with pica. The two groups did not differ significantly in terms of being in the youngest age category (18-44 years old), number of years in a lifetime spent in an institution, length of stay in their current facility, having mental retardation or other cause of ID, and the frequency of borderline, severe, and profound levels of ID.

Table 4 Demographic Characteristics by Presence of Pica

Characteristics	Pica (n=220)	No Pica (n=788)	
	% (n)	**% (n)**	**p-value**
Age Category			
18-44 years	25.7 (55)	25.6 (196)	.0065
45-54 years	53.3 (114)	43.0 (330)	
55+ years	21.0 (45)	31.4 (241)	
Male	72.3 (159)	59.1 (463)	.0004
Nature of ID			
Mental Retardation	32.3 (71)	35.1 (277)	.43
Down's syndrome	3.6 (8)	10.3 (81)	.002
Autism	7.3 (16)	2.4 (19)	.001
Prader-Willi syndrome	0.0 (0)	0.0 (0)	-
Other	56.8 (125)	52.2 (411)	.21
Severity of ID			
Borderline	0.5 (1)	0.4 (3)	1.0
Mild	0.0 (0)	3.2 (25)	.01
Moderate	1.8 (4)	10.0 (78)	.0001
Severe	18.2 (40)	16.6 (130)	.58
Profound	50.5 (111)	51.0 (399)	.89
Undocumented	29.1 (64)	18.9 (148)	.001

Characteristics	**Mean (SD)**	**Mean (SD)**	**p-value**
Age	50.0 (8.2)	52.0 (9.7)	.003
Age at which person left family home	7.3 (4.3)	9.8 (8.3)	.001
Number of years (lifetime) spent in an institution	42.1 (8.4)	41.4 (10.8)	.38
Length of stay in facility	39.5 (8.8)	38.8 (11.2)	.28

5.3.1.2 Functional Characteristics by Presence of Pica

Tables 5 to 7 present information on various domains of adaptive functioning, including communication, cognition, ADLs, and mobility. Overall, persons with pica were more likely to be nonverbal (87.3% vs. 65.3%), and had greater impairments in expressive and receptive communication (*t*=-5.92, *p*<.0001, *t*=-5.50, *p* <.0001, respectively*)*. With regard to expression, persons with pica had a higher rate of being rarely or never understood relative to those without pica. Likewise, a higher proportion of persons with pica scored as sometimes understands to rarely or never understands.

Table 5 Communication by Presence of Pica

Communication	**Pica (n=220)**	**No Pica (n=788)**	
	% (n)	**% (n)**	**p-value**
Non-verbal	87.3 (192)	65.3 (514)	<.0001
Expression			
Understood	2.3 (5	4.9 (39)	
Usually understood	3.2 (7)	12.1 (95)	<.0001
Often understood	9.5 (21)	10.0 (79)	
Sometimes understood	21.8 (48)	29.2 (230)	
Rarely or never understood	63.2 (139)	43.8 (345)	
Comprehension			
Understands	2.3 (5)	5.7 (45)	
Usually understands	5.4 (12)	18.3 (144)	<.0001
Often understands	13.2 (29)	14.5 (114)	
Sometimes understands	50.9 (112)	37.4 (295)	
Rarely or never understands	37.4 (295)	24.1 (190)	
	Mean (SD)	**Mean (SD)**	**p-value**
Expression	3.4 (0.9)	2.9 (1.2)	<.0001
Comprehension	3.0 (0.9)	2.6 (1.2)	<.0001

Table 6 presents the frequencies for the embedded scales measuring cognitive performance (CPS), activities of daily living (ADL-H), instability of health (CHESS), and the means (and standard deviations) for instrumental activities of daily living (IADL-C) by presence of pica. Between group differences were significant for the CPS, ADL-H, and IADL-C, but not for the CHESS. A higher proportion of persons with pica than those without scored in the severely impaired range of cognition (65.4% compared to 47.2%). It is noteworthy, however, that a smaller proportion of persons with pica scored as being very severely impaired in cognition than those without pica (12.3% compared to 22.9%). On the ADL-H subscale, the majority of persons with pica scored as requiring moderate ADL assistance (level 1 extensive assistance) compared to those without pica (59.5% compared to 36.8%). A lower proportion of persons with pica required more extensive assistance in ADLs, including level 2 extensive assistance (3.2% compared to 5.6%), dependence on others (12.7% compared to 18.8%), and total dependence on others (8.2% compared to 19.6%). IADL Capacity means scores between those with and without pica were significantly different (47.5 compared to 46.9) indicating that persons with pica were rated as less capable of carrying out IADLs on their own. Lastly, although the groups were comparable with respect to decline in functioning as measured by the CHESS, a significant proportion had some health instability (approximately 17%).

Table 6 Functional Characteristics by Presence of Pica

	Pica (n=220)	**No Pica (n=788)**	
	% (n)	**% (n)**	**p-value**
Cognitive Performance Scale			
0 = Intact	0.0 (0)	0.3 (2)	<.0001
1 = Borderline intact	0.0 (0)	3.8 (30)	
2 = Mild cognitive impairment	0.0 (0)	4.1 (32)	
3 = Moderate cognitive impairment	10.9 (24)	12.8 (100)	
4 = Moderate to severe cognitive impairment	11.4 (25)	8.9 (70)	
5 = Severe cognitive impairment	65.4 (144)	47.2 (369)	
6 = Very severe cognitive impairment	12.3 (27)	22.9 (179)	
Activities of Daily Living Hierarchy(ADL-H)			
0= Independent	0.5 (1)	5.0 (39)	<.0001
1 = Supervision required	7.3 (16)	9.4 (74)	
2 = Limited assistance required	8.6 (19)	4.8 (38)	
3 = Extensive assistance required; level 1	59.5 (131)	36.8 (290)	
4 = Extensive assistance required; level 2	3.2 (7)	5.6 (44)	
5 = Dependent on others	12.7 (28)	18.8 (148)	
6 = Totally dependent on others	8.2 (18)	19.6 (154)	
CHESS			
0 =No health instability	82.6 (180)	83.3 (646)	.78
1-4 = Health instability	17.4 (38)	16.7 (129)	
	Mean (SD)	**Mean (SD)**	**p-value**
Instrumental Activities of Daily Living: Capacity (scores range 0-48)	47.5 (1.3)	46.9 (3.0)	.0002

Table 7 contains mobility characteristics by the presence of pica. The results indicate that persons with pica were less restricted in their walking. In particular, they were less likely to need limited assistance to total dependence when walking between locations (14.3% vs. 26.6%). As can also be seen in Table 7, a smaller proportion of persons with pica used a wheelchair than did persons without pica (20.4% vs. 41.8%).

Table 7 Mobility Characteristics by Presence of Pica

	Pica (n=220)	**No Pica (n=788)**	
	% (n)	**% (n)**	**p-value**
Walking			
Independent	65.8 (129)	60.7 (363)	.001
Set-up help to supervision	19.9 (39)	12.7 (76)	
Limited assistance to total dependence	14.3 (28)	26.6 (159)	
Used a wheelchair	20.4 (45)	41.8 (329)	<.0001

5.3.1.3 Behavioural Characteristics and Psychiatric Diagnoses by Presence of Pica

Table 8 presents information on the prevalence of a number of challenging behaviours by the presence of pica. An individual was identified as showing one of these forms of challenging behaviour if they were rated as having any presence of the behaviour regardless of the frequency. A number of specific forms of challenging behaviours occurred more frequently among persons identified with pica. These were: wandering, physical abuse, socially inappropriate or disruptive behaviour, inappropriate sexual behaviour or disrobing, self-injurious behaviour, destructive behaviour, rumination, and polydipsia. A smaller proportion of persons with pica displayed verbal abuse. The most frequent behaviours among persons with pica were socially inappropriate or disruptive behaviour, self-injury, and wandering. Persons with pica showed a greater number of behaviours. On average, persons with pica exhibited 4.1 challenging behaviours compared to 2.6 in those without pica (*t* = -8.3, *p* <.0001).

Table 8 Challenging Behaviours by Presence of Pica

	Pica (n=220)	**No Pica (n=788)**	
	% (n)	**% (n)**	**p-value**
Wandering	55.2 (122)	23.0 (179)	.0001
Verbal abuse	11.4 (25)	21.9 (170)	.001
Physical abuse	41.8 (92)	30.8 (240)	.002
Socially inappropriate or disruptive behaviour	64.1 (141)	45.5 (353)	<.0001
Inappropriate public sexual behaviour/public disrobing	35.6 (78)	12.8 (99)	<.0001
Self-injurious behaviour	59.5 (131)	35.6 (277)	<.0001
Destructive behaviour	40.4 (89)	24.4 (190)	<.0001
Outburst of Anger	49.5 (108)	37.3 (289)	.001
Resists care	26.5 (58)	17.2 (134)	.002
Rumination	21.0 (46)	7.9 (62)	<.0001
Polydipsia	11.8 (26)	2.8 (22)	<.0001
	Mean (SD)	**Mean (SD)**	**p-value**
Total number of behaviours	4.1 (2.6)	2.6 (2.4)	<.0001

Table 9 presents the frequencies for adults with and with pica for the embedded scales measuring aggression (ABS) and depression (DRS). A greater proportion of adults with pica scored as mildly aggressive (59.6% vs. 43.8%), and severely aggressive (14.2% vs. 12.9%) compared to those without pica. The distributions on the DRS scale were similar between the two groups, however. Approximately 12% of persons with and without pica had clinically relevant depression.

Compared to persons without pica, persons with pica were less likely to have a diagnosis of dementia (See Table 10). No significant differences existed between the groups for schizophrenia/psychotic disorders, mood disorders, and anxiety disorders.

Table 9 Aggression and Depression by Presence of Pica

	Pica (n=220)	**No Pica (n=788)**	
	% (n)	**% (n)**	**p-value**
Aggressive Behavioural Scale			
None (0)	26.1 (57)	43.3 (335)	
Mild (1-4)	59.6 (130)	43.8 (339)	<.0001
Severe (5+)	14.2 (31)	12.9 (100)	
Depression Rating Scale			
No signs of depression (0-2)	87.2 (191)	87.7 (683)	.85
Clinically relevant depression (3+)	12.8 (28)	12.3 (96)	

Table 10 Psychiatric Diagnoses by Presence of Pica

	Pica (n=220)	**No Pica (n=788)**	
	% (n)	**%(n)**	**p-value**
Dementia/Delirium	2.3 (5)	6.9 (53)	p=.01
Schizophrenia/Psychosis	11.0 (24)	7.9 (61)	p=.14
Mood disorders	12.4 (27)	11.2 (87)	p=.62
Anxiety disorders	9.3 (20)	9.1 (70)	p=.92

5.3.2 Multivariate Analyses

Multivariate statistical analyses were undertaken to identify which characteristics acted as key correlates of whether a person is likely to exhibit pica. By convention, the severity of ID is used as a measure of cognitive impairment for the ID population. However, it was not used as a measure of cognitive impairment for the present analysis because 21.1% (n=212) of the sample did not have this information documented. Instead, the cognitive performance scale (CPS) was used as a proxy for severity of ID (they have been found to be highly correlated in previous research). The literature and results from the bivariate analyses were used to identify the independent variables to be included in the multivariate logistic model for predicting the occurrence of pica. The following independent variables were selected for inclusion in the model: age, male, CPS, ADL-H, non-verbal communication, autism, and dementia. Other variables, such as expression and comprehension were highly collinear with non-verbal communication and thus to avoid redundancy were not included. The CPS was transformed due to its curvilinear relationship with pica to adequately model this relationship. A quadratic term (squared term) for CPS was added to the model in which the first order term of CPS was already included in the model. The coefficient of the quadratic term for CPS was negative and significant whereas the CPS term alone was found to be positive and significant indicating adequate fit of the data. Age and dementia were not significant and therefore were not included in the final model.

Multicollinearity

The degree of inter-correlation among the independent variables was also assessed to inform variable selection for building a logistic regression model. Pairwise multicollinearity was evaluated with a matrix of correlations between the independent variables using the Spearman rank correlation coefficient for ranked categorical and binary variables. A coefficient of 0.70 was determined a priori, as a conservative cut-off, above which variables were considered to display evidence of multicollinearity. None of the correlations exceeded the cut-point (range of 0.01 to 0.69) even though they were statistically significant. For example, in the assessment of the multicollinearity between non-verbal communication and severe CPS, Spearman's rho was equal to 0.51 and so both variables were included in the initial model for determining characteristics that predict the presence of pica. Multicollinearity among three or more of the independent variables was also examined. Once again, there was no evidence of multicollinearity as the variance inflation factors (VIF) were quite small for all independent variables and they did not surpass the cut-off of 4 (range of VIF was 1.03 to 2.11). Further, the condition indices yielded values suggesting weak associations among the independent variables (all less than a value of 30).

The Assessment of Confounding and Interaction

Following the assessment of multicollinearity, specific two-way interaction terms were assessed. The relationship between autism and pica was examined, controlling for severe cognitive impairment. Severe cognitive impairment was also statistically controlled for when assessing the relationship between non-verbal communication and pica. There was no indication that the relationship between autism and pica was confounded by severe cognitive impairment (the crude odds ratio and the adjusted odds ratio were similar), nor was there any evidence of an interaction between autism and severe cognitive impairment (Breslow-day-tarone test for homogeneity of the odds ratio, X^2=0.46, p=.50). While there was no indication that any confounding was due to severe cognitive impairment with respect to the relationship between non-verbal communication and pica, there was evidence of an interaction (Breslow-day-tarone test for homogeneity of the odds ratio, X^2=4.02, p=.045). Specifically, the effect of non-verbal communication on pica was much stronger for those with mild/moderate cognitive impairment than for those with severe/very severe cognitive impairment. The product of non-verbal communication and cognitive performance was further assessed in concert with all other variables using logistic regression, including each component part of the product term (non-verbal communication and CPS itself). The interaction, however, was non-significant in combination with all other variables and its main effects. Lastly, the interaction of autism and non-verbal communication was assessed using logistic regression and was also found to be non-significant.

Final Logistic Regression Model

The results of this final model for pica are shown in Table 11. The final model indicates that being male, CPS, having autism, being non-verbal, and ADLs were all independently associated with the presence of pica. According to the odds ratios, an individual who is male had 1.59 times the odds of having pica, those with autism had 2.20 times the odds of having pica, and those who were non-verbal had 3.92 times the odds of having pica. Conversely, individuals had 0.79 times decreased odds of having pica for every point increase on the ADL-H scale. This means that the chances of an individual exhibiting pica decreases as

ADL impairment increases. Lastly, the results indicate that there was a significant quadratic relationship between level of cognitive impairment and pica and is discussed in more detail below.

There was good evidence that the model fit the data well and there was no evidence to support the null hypothesis that the parameter estimates are collectively equal to zero (Wald Chi-Square=83.04, df=6, p < .0001). Goodness of fit calculations also indicated that the final model had strong predictive power with a c statistic of 0.71, where 1 indicates perfect prediction and 0.5 indicates chance prediction.

Table 11 Final Multivariate Logistic Regression Model Predicting Pica Among Adults with ID

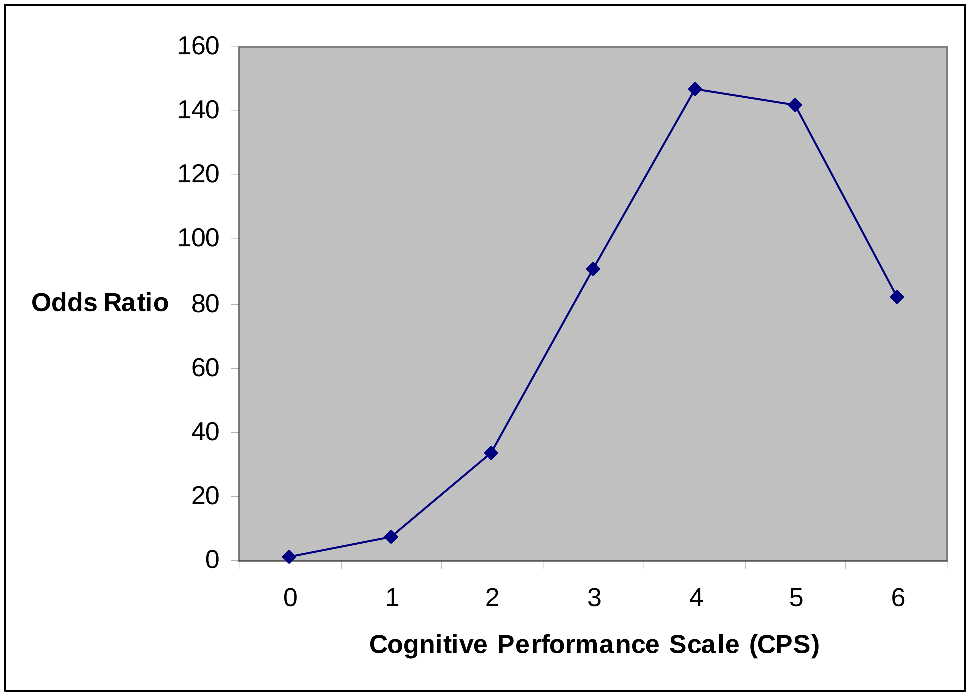
	Parameter Estimate	Standard Error	Odds Ratio	95% C.I.	C Statistic
Male	0.46*	0.18	1.59	1.12-2.25	.71
CPS	2.27*	0.68	-	-	
CPS²	-0.26*	0.08	-	-	
Autism	0.79*	0.37	2.20	1.05-4.59	
Non-verbal	1.37**	0.25	3.92	2.41-6.38	
ADL-H	-0.23*	0.08	0.79	0.68-0.92	

*p<.05 **p<.0001

Note: the odds ratio for CPS is not available due to its transformation in the equation

Figure 1 illustrates the quadratic relationship between CPS and pica. Specifically, the plot displays the odds of pica separately for each level of the CPS, to illustrate the changing relationship with severity of CPS. The odds of pica rapidly rises with increasing levels of cognitive impairment but then declines at the severest levels of cognitive impairment, particularly among those with very severe cognitive impairment (level 6).

Figure 1 The Quadratic Relationship Between the Cognitive Performance Scale (CPS) and Pica: Odds Ratio by Level of CPS



5.4 Social Characteristics of Pica

5.4.1 Bivariate Analyses

The social characteristics of persons with and without pica are presented in Table 12. Individuals with pica were less likely to have a strong and supportive relationship with family and as a result had lower rates of social contact with family and other social relations (e.g., visit, other contact, and overnight stay). Both groups showed similar rates of interpersonal conflict. In terms of social engagement, individuals with pica showed lower rates of participation in social activities of long-standing interest and ease when interacting with others over the last 30 days. Likewise, individuals with pica also demonstrated lower rates of involvement in activities of their residential setting and being at ease doing planned activities compared to individuals without pica.

Table 12 Social Characteristics by Presence of ID

	Pica (n=220)	**No Pica (n=788)**	
	% (n)	**% (n)**	**p-value**
Strong and supportive relationship with family	27.0 (57)	45.1 (343)	<.0001
Social contact with family/social relation in the last 30 days			
Visit	10.5 (23)	19.5 (153)	.002
Other contact (i.e., telephone)	4.6 (10)	12.0 (94)	.002
Overnight stay	0.5 (1)	2.8 (22)	.04
Participation in social activities of long-standing interest	25.6 (56)	40.9 (320)	<.0001
Interpersonal conflict (Last 3 days)			
Conflict with family or friends	0.9 (2)	1.9 (15)	.31
Conflict with other clients or staff	3.7 (8)	5.0 (39)	.42
Family/close friends hostile toward person	0.0 (0)	0.5 (4)	.29
Sense of Involvement (Last 3 days)			
At ease interacting with others	47.7 (105)	59.2 (465)	.003
At ease doing planned activities	34.6 (76)	50.5 (396)	<.0001
Pursues involvement in activities of residential setting or community	15.5 (34)	21.7 (170)	.04

Data pertaining to the different types of activity involvement in the last 30 days by the presence of pica is summarized in Table 13. Comparisons between those with and without pica indicated that those with pica were less likely to be involved in collecting items, computer activities, conversing/communicating with others, crafts or arts, gardening, and watching TV or listening to the radio. The groups were comparable with respect to the following types of activities: cards, games, puzzles; exercise or sports; helping others; music or singing; pets; reading/writing/crossword puzzles; spiritual or religious activities; trips or shopping; and walking or wheeling outdoors. When the different categories of activities were combined to form an overall measure of the total percentage of involvement in any form of activity, those who had pica engaged significantly less in activities than those without pica.

Table 13 Types of Activity Involvement by Presence of Pica

Type of Activity	Pica (n=220)	No Pica (n=788)	
	% (n)	% (n)	p-value
Cards, other games, puzzles	9.1 (20)	13.7 (107)	.07
Collecting	6.4 (16)	15.0 (118)	.001
Computer activities	1.8 (4)	6.0 (47)	.01
Conversing	26.4 (58)	38.7 (303)	.001
Crafts or arts	6.4 (14)	21.7 (170)	<.0001
Exercise or sports	20.1 (44)	23.3 (183)	.31
Garden or plants	1.8 (4)	5.7 (45)	.02
Helping others	21.8 (48)	19.3 (152)	.41
Music or singing	41.8 (92)	48.5 (381)	.08
Pets	2.3 (5)	4.5 (35)	.14
Reading, writing, or crossword puzzles	3.2 (7)	5.8 (46)	.12
Spiritual or religious activities	26.4 (58)	31.9 (250)	.12
Trips or shopping	22.8 (50)	23.0 (180)	.97
Walking or wheeling outdoors	49.5 (108)	52.2 (410)	.48
Watching TV or listening to radio	69.4 (152)	79.9 (629)	.001
Involvement in any activity	78.6 (169)	89.0 (672)	<.0001

5.4.2 Multivariate Analyses

The extent to which pica contributes to impairment or problems in the social domain was further examined using multivariate statistical techniques. This will contribute to a better understanding of the nature and consequences of pica. Logistic regression analysis was conducted to determine the impact of pica while controlling for other factors for predicting absence of a strong and supportive relationship with family, absence of social contact with family or long-standing social relation, lack of participation in social activities of long-standing interest, and lack of involvement in any type of activity. Tables 14 to 17 present the results of these logistic regression analyses with pica as the independent variable and each type of social characteristic as the dependent variable. Table 14 presents the relationship between pica and the absence of a strong and supportive relationship at the multivariate level. Pica was examined in combination with age (10 year interval), male, length of stay (10 year interval), cognitive functioning, self-care skills, and aggression. Male, length of stay, self-care skills, and aggression were unrelated to the outcome. Pica, age, and cognition were significantly associated with increased odds of absence of a strong and supportive relationship with family (2.26, 1.39, 1.44, respectively). The odds ratio indicates that individuals with pica were 2.26 times more likely to not have a strong and supportive relationship with their family compared to those without pica. Thus, pica was independently, and positively related to the absence of a strong and supportive relationship with family, while controlling for all other significant variables.

Table 14 Association between Pica and Absence of A Strong and Supportive Relationship with Family

	Parameter Estimate	**Standard Error**	**Odds Ratio**	**95% C.I.**
Pica	.81**	.18	2.26	1.60-3.22
Age (10 years)	.03**	.01	1.39	1.20-1.62
Cognitive Performance Scale	.37**	.06	1.44	1.29-1.62

*p <.05, ** p<.001

A second model examined the relationship between pica and the absence of social contact in the last 30 days from a family member or a social relation. The dependent variable-absence of social contact-refers to the absence of either a visit, other contact (letter, card), or overnight stay in the last 30 days with a family member/social relation. The results of the multivariate model are summarized in Table 15. When other factors were taken into account, pica remained a significant correlate in predicting the absence of social contact. Following the removal of variables that failed to reach significance (age, male, self-care skills, aggression), only three variables remained: pica, length of stay, and cognitive functioning. Pica was associated with increased odds of absence of social contact in the last 30 days. Persons with pica had 1.89 times the odds of not having contact with a family member or social relation in the last 30 days.

Table 15 Association between Pica and Lack of Contact from Family members or Social Relation in the last 30 days

	Parameter Estimate	Standard Error	Odds Ratio	95% C.I.
Pica	0.64*	0.23	1.89	1.23-2.99
Length of Stay (10 years)	0.02*	0.01	1.18	1.02-1.38
Cognitive Performance Scale	0.61**	0.07	1.83	1.61-2.10

*p <.05, ** p<.001

A third model examined whether having pica was related to the absence of participation in social activities of long-standing interest. Results summarizing the final multivariate model are presented in Table 16. The final model included only variables that were significant: pica, cognitive functioning, and autism. When compared to individuals without pica, individuals with pica showed a higher odds of not participating in social activities (OR=1.79).

Table 16 Association between Pica and Lack of Participation in Social Activities of Long-Standing Interest

	Parameter Estimate	Standard Error	Odds Ratio	95% C.I.
Pica	0.58*	0.18	1.79	1.25-2.57
Cognitive Performance Scale	0.72**	0.07	2.05	1.79-2.35
Autism	1.62*	0.53	5.07	1.81-14.23

*p <.05, ** p<.001

A fourth model examined the association between pica and the lack of involvement in any type of recreational activity (Table 17). After adjusting for potential confounders, the following variables were found to be significant predictors of lack of activity involvement:

pica, cognitive functioning, ADLs, and autism. Persons with pica were 2.05 times more likely not to be involved in any type of activity.

Table 17 Association between Pica and Lack of Activity Involvement

	Parameter Estimate	Standard Error	Odds Ratio	95% C.I.
Pica	0.72*	0.21	2.05	1.36-3.11
Cognitive Performance Scale	0.96**	0.20	2.62	1.78-3.86
Activities of Daily Living Scale	-0.22*	0.09	0.80	0.66-0.96
Autism	1.05*	0.41	2.86	1.27-6.44

*p <.05, ** p<.001

5.5 Medical Characteristics of Pica

Mineral deficiency and gastrointestinal (GI) conditions were examined. Frequencies of the gastrointestinal symptoms and the presence of gastrointestinal disorder among those with and without pica are listed in Table 18. The results show that adults with pica had a higher rate of acid reflux compared to those without pica. Although typically more prevalent in persons with pica, they had a significantly lower prevalence of gastrointestinal disorder. Persons with and without pica were equally likely to experience mineral deficiency, constipation, diarrhea, change in appetite, nausea, and vomiting.

Table 18 Frequency of Mineral Deficiency and Gastrointestinal (GI) Symptoms by Presence of Pica

GI Symptoms	**Pica (n=220)**	**No Pica (n=788)**	
	% (n)	**% (n)**	**p-value**
Mineral deficiency/Anemia	1.8 (4)	1.1 (9)	.50
Acid reflux	25.1 (55)	17.2 (135)	.01
Constipation	28.8 (63)	33.6 (263)	.17
Diarrhea	11.8 (26)	9.3 (73)	.27
Increase/decrease in normal appetite	9.5 (21)	6.4 (50)	.10
Nausea	2.3 (5)	3.0 (24)	.54
Vomiting	4.1 (9)	5.3 (42)	.46
Medical Diagnoses			
Gastrointestinal Disorder	16.4 (36)	24.1 (190)	.01

5.6 Management of Pica

5.6.1 Bivariate Analyses

5.6.1.1 Interventions by Presence of Pica

Table 19 provides a summary of the various services and training programs that persons with and without pica were offered/received in the last 30 days. The most frequent services received by persons with pica were behaviour management (42.2%), followed by sensory stimulation (42.3%), and self-care skills training (24.1%). Individuals with pica were more likely to receive behaviour management (42.2% vs. 24.1%) and self-care skills (24.1% vs. 16.1%) relative to those without pica.

Table 19 Focus of Interventions by Presence of Pica

Interventions	**Pica (n=220)**	**No Pica (n=788)**	
	% (n)	**% (n)**	**p-value**
Self-care skills training	24.1 (53)	16.1 (126)	.01
Community skills training	5.9 (13)	8.7 (68)	.19
Social skills training	18.2 (40)	14.5 (114)	.18
Cognitive skills training	3.6 (8)	5.0 (39)	.41
Education on special topics	0.5 (1)	0.8 (6)	.63
Behaviour management	42.2 (92)	24.1 (188)	<.0001
Sensory stimulation programs	42.3 (93)	41.2 (323)	.76

5.6.1.2 Psychotropic Medication by Presence of Pica

Psychotropic medication was investigated among persons with and without pica. As shown in Table 20, persons with pica were significantly more likely to be prescribed an antipsychotic medication (atypical and typical forms). However, the groups were similar with respect to receiving both atypical and typical antipsychotics simultaneously. No significant differences were found between the groups for the prescription of antidepressants, hypnotics/sedatives, and anticonvulsants.

Table 20 Psychotropic Medication by Presence of Pica

Psychotropic Medication	Pica (n=220)	No Pica (n=788)	
	% (n)	% (n)	p-value
Antipsychotics	55.4 (122)	36.2 (286)	<.0001
Atypical	36.8 (81)	22.5 (178)	<.0001
Typical	27.9 (60)	19.8 (152)	.01
Both	9.1 (20)	6.3 (50)	.15
Antidepressants	20.0 (44)	19.6 (155)	.90
Hypnotics/Sedatives	64.1 (141)	60.4 (477)	.32
Anticonvulsants	56.4 (124)	52.0 (411)	.25

5.6.1.3 Supervision by Presence of Pica

As shown in Table 21, a higher proportion of individuals with pica were rated as receiving 16 to 24 hours compared to persons who do not engage in pica (22.9% versus 15.4%). In contrast, a lower proportion of individuals with pica received 1 to 4 hours of support (20.2 % versus 35.9%). However, the amount of one-to-one direct care received was relatively similar between the two groups for the following hours: up to 1 hour support, 4 to 8 hours of support, and 8 to 16 hours of support.

Table 21 Staff Ratings of One-to-One Supervision by Presence of Pica

Hours	**Pica (n=220)**	**No Pica (n=788)**	
	% (n)	**% (n)**	**p-value**
Up to 1 hour	0.9 (2)	1.4 (11)	.0003
1-4 hours	20.2 (44)	35.9 (277)	
4-8 hours	39.9 (87)	33.9 (262)	
8-16 hours	16.1 (35)	13.3 (103)	
16-24 hours	22.9 (50)	15.4 (119)	

Staff also rated the change in need of one-to-one support after community placement. As evident from Table 22, the need for the amount of supervision to increase after community placement was significantly higher among individuals with pica compared to those without pica (50.7% vs. 38.1%). It should be noted that no one with pica was rated as needing a decrease in the amount of supervision upon community placement.

Table 22 Staff Ratings of the Change of One-to-One Supervision Upon Community Placement by Presence of Pica

	Pica (n=220)	**No Pica (n=788)**	
	% (n)	**% (n)**	**p-value**
No Change	49.3 (107)	61.6 (474)	.003
Supervision to Increase	50.7 (110)	38.1 (293)	
Supervision to Decrease	0.0 (0)	0.3 (2)	

5.6.2 Multivariate Analyses

Multivariate logistic regression showed that persons with pica had increased likelihood of being prescribed antipsychotic medication, while controlling for a diagnosis of schizophrenia, and aggressive behaviour (Table 23). Other factors such as cognitive functioning, and specific psychotic symptoms (hallucinations and delusions) were found not to be significant predictors of antipsychotic medication. Persons with pica were 1.96 times more likely to be prescribed an antipsychotic compared to persons without pica.

Table 23 Association between Pica and Antipsychotic Medication

	Parameter Estimate	**Standard Error**	**Odds Ratio**	**95% C.I.**
Pica	0.67**	0.17	1.96	1.42-2.72
Schizophrenia	2.19**	0.34	8.94	4.62-17.31
Aggressive Behaviour Scale	0.21**	0.03	1.23	1.15-1.31

*p <.05, ** p<.001

A multivariate model was developed to assess the contribution of pica on the amount of support received by staff while adjusting for potential confounders. As a review, the dependent variable is the amount of one-to-one care an individual received in the last 3 days. The amount of supervision variable is comprised of 6 ordered categories, with each category representing an increasing amount of one-to-one support in hours (e.g., none, up to one hour, between 1 and 4 hours, between 4 and 8 hours, between 8 and 16 hours, and between 16 and 24 hours). For ease of interpretation, these ordinal categories of supervision were collapsed to a binary dependent variable where 0=8 hours or less of supervision and 1=8 hours or more of supervision in order to fit a binary logistic regression. Therefore the logistic regression modelled the probability of persons receiving 8 hours or more of supervision.

The initial model controlled for the following characteristics: male, age, aggression, self-injury, cognitive functioning, and self-care skills as measured by the ADL-H scale. Following the removal of variables where the coefficient failed to reach significance, only two variables remained: pica and aggression. The results of this model are presented in Table 24. Individuals with pica had 1.49 times the odds of receiving 8 hours or more of supervision compared to those without pica. The odds of receiving 8 hours or more of supervision also increased for every point increase on the ABS scale (1.14), suggesting that severity of aggression is associated with more intensive hours of supervision.

Table 24 Association between Pica and the Amount of One-to-One Supervision

	Parameter Estimate	**Standard Error**	**Odds Ratio**	**95% C.I.**
Pica	.40*	.16	1.49	1.09-2.06
Aggressive Behaviour Scale	.13**	.03	1.14	1.07-1.20

*p <.05, ** p<.001

6.0 Discussion

This study of pica among individuals with ID had four objectives: 1) to determine the prevalence of pica among facility and community settings, 2) correlates of pica, 3) social and medical characteristics of pica, and 4) the management practices of pica. Following is a discussion of the results.

Prevalence

The prevalence of pica was 22.0% and 3.0% in facility and community settings, respectively. Several studies have also shown similar rates, and that pica is generally more prevalent in institutional than community settings (Ali, 2001). There are several explanations as to why pica is often associated with residential setting. Some suggest that the restrictive setting of institutions causes challenging behaviours. However, the more likely explanation is that having severe or profound ID and pica was a cause for being placed in an institution years ago because of the need for constant supervision. Further, with the mandate to close institutions in Ontario in the 1970s, the remaining individuals left in Ontario's facilities for persons with ID most likely have more complex needs or behaviours that are more difficult to manage. As such, a large proportion of these individuals have pica in the facilities.

Findings indicate that the majority of persons with pica did not engage in the behaviour during the assessment time period while only one third of persons showed pica on a daily or almost daily basis (last 3 days). This frequency pattern probably stems from the fact that pica is well managed in the facility setting. If it were not for the behaviour management and the supervision that they received, these persons would likely have more opportunity to engage in pica more often and with greater intensity.

Factors Associated with Pica

Pica was found to be a function of a number of factors, including cognitive functioning, activities of daily living, being non-verbal, having autism, and being male. This study replicated the association between cognitive functioning and pica. Although the literature suggests that pica becomes more prevalent with increasing levels of ID, implying a linear relationship, our results suggest that this statement is too simplistic and inaccurate. Rather than being linear, the relationship between levels of cognitive impairment and pica is best described as a curvilinear in which pica increases with levels of cognitive impairment and then declines with very severe cognitive impairment. The majority persons with pica were in the severe range rather than the very severe range of cognitive impairment suggesting that some degree of cognitive skill is needed in order to perform pica behaviour.

Pica was also found to be related to what a person is capable of physically as measured by the ADL Hierarchy scale. The odds of pica decreased with greater levels of ADL impairment indicating that one needs some ADL functioning to be able to perform pica. Bivariate results showed that pica manifested itself most often by individuals who presented moderate levels of ADL impairment (i.e., ADL value of 3). Specifically, they were more able to eat and walk independently (less likely to use a wheelchair) compared to their counterparts without pica suggesting that one needs to be independent in particular ADLs to perform pica. This relationship is consistent with the literature that challenging behaviour decreases with functional and medical complexity (Emerson et al., 2001). Although it may be self-evident that an individual needs a minimal level of physical functioning to engage in pica behaviour, this has not been previously reported in the literature. The differential influence of level of cognitive impairment and activities of daily living on pica is clear in this study and is a pattern commonly observed in other populations, such as among persons with dementia who display aggressive behaviours (Cohen-Mansfield, Marx, & Rosenthal, 1990).

Persons with pica were over four times more likely to be non-verbal than those without pica. Although non-verbal communication and levels of cognitive impairment were moderately associated with each other, non-verbal communication was independently associated with pica. The relationship between pica behaviour and communication may be explained in the following way. Perhaps at an early age persons with ID who are non-verbal/aphasic tended to seek out non-social stimulation because of their difficulties in communicating with others. Many may not have developed elaborate gestural communication or were taught the use of picture exchange to communicate their needs or wants, as these methods are likely dependent on cognitive ability. In addition, social isolation may also have played a role. Persons who are non-verbal may have been more likely to be excluded from social interactions and hence had fewer meaningful social exchanges. As a consequence, persons who are non-verbal may have turned to other sources for stimulation. Through incidental learning they may have developed stereotyped movements, self-injury (skin-picking, hand-biting), or ingested substances for stimulation. Pica then becomes reinforced overtime because of the inherent sensory stimulation that it produces. Other studies have reported similar associations between communication deficits and pica (Dudley et al., 1999), and other challenging behaviours (Borthwick-Duffy, 1994; Emerson et al., 2001).

Persons with pica were also more likely to have a diagnosis of autism. This is the first study to show that autism is independently related to pica while taking into account cognitive, self-care, and communicative skills. Previous studies have only reported this relationship at the bivariate level. A number of propositions can be put forth to explain the autism-pica association. The co-occurrence may be linked to the profound social and communicative deficits inherent to autism, heightening the risk for social exclusion and inappropriate behaviours, such as pica. In other words, having autism makes one more liable to seek non-social forms of stimulation. The literature also suggests that persons with autism show more challenging behaviours than those without autism and ID, especially repetitive behaviours (APA, 2001). For example, stereotyped movements, self-injury, and obsessions and compulsions are more common among persons with autism (APA, 2001). Pica may simply be another topography of repetitive behaviour that has not received much attention in persons with autism. Sensory disturbances in autism may offer yet another explanation for the link between autism and pica. For example, researchers have noted that the different sensory processing among persons with autism makes them more sensitive or under-sensitive to stimulation (O'Neill & Jones, 1997). Pica may therefore be a consequence of a dysfunction in sensory regulation. Thus, persons with autism may be more prone to seek out sensory stimulation in the form of pica. We caution, however, that this finding is based on a small sample of persons with autism and future studies need to look at larger samples. Lastly, consistent with previous research, pica was found to be more common in males.

Other Characteristics

The finding that persons with pica had higher rates of an undocumented level of ID may be due to the fact that they were difficult to assess given that the majority were non-verbal. The frequency and total number of 'other 'challenging behaviours was greater among persons identified with pica. Of particular interest is the higher prevalence of wandering behaviour, destructive behaviour, physical abuse, inappropriate sexual behaviour and public disrobing, rumination, and polydipsia among persons with pica. We propose that many of these behaviours may be intertwined with pica or play a role in facilitating the behaviour. For example, the increased rate of wandering behaviour among those with pica is probably a reflection of them searching for items to ingest in their environment. To this end, we would argue that wandering here is goal-directed and a reflection of the person’s motivation to seek out items to ingest.

Other behaviours (higher rates of aggression) may be reactions to being prevented from searching for or ingesting inedibles. As indicated in the literature, persons with pica may become physically aggressive (e.g., push or hit people) when they are blocked from picking up an item or when items are taken away from them (Danford & Huber, 1982; Hagopian & Adelinis, 2001).On the other hand, polydipsia and rumination could be regarded as different manifestations of pica, in that they both are consumatory behaviours. Alternatively, these cluster of behaviours may serve a similar function to pica in that they are self-stimulatory (involve oral stimulation) (Vollmer, 1994).

Management of Pica

To our knowledge, this study is the first to show quantitatively that persons with ID and pica behaviour require more supervision relative to persons without pica. This is consistent with prior reports that persons with pica require close and constant supervision from family and staff. These earlier studies, however, were based upon anecdotal evidence. Having pica increased the likelihood of receiving 8 hours or more of supervision. As well, an important subgroup of persons with pica were significantly more likely to receive the highest hours of support (16 to 24 hours) suggesting within group differences. In other words, persons with pica may vary with resource intensity depending on the frequency and severity of their pica. Overall, these findings support the notion that particular subgroups of persons with ID require more resources than others.

Behaviour management and self-care skills were more likely to be used to manage pica than other forms of interventions. While not a distinguishing intervention for those with pica, sensory stimulation was also frequently reported. It should be noted that other important interventions were not measured in this study. Consistent with previous research, the predominant approach to deal with pica is through behaviourally oriented approaches (Burke & Smith, 1999; Carter & Wheeler, 2004; Stiegler, 2005).

Persons with pica were more likely to be prescribed antipsychotic medications compared to those without pica. It is unclear; however, in this study whether antipsychotics were used to specifically reduce the frequency or severity of pica behaviour. This is due to the fact that information on the reason for prescribing each medication was not collected. Nonetheless, the higher rate of antipsychotic use among persons with pica is noteworthy as only a minority of persons with pica had a diagnosis of a psychotic disorder (11.0%), the proper indication for antipsychotic medication. Given the behavioural complexity of persons with pica (greater number of challenging behaviours), it may be the case that antipsychotic medication is prescribed for reducing overt behaviours among persons with pica such as agitation or aggression. Alternatively, antipsychotic medication may be used inappropriately for its tranquillising properties to reduce persons with pica from having the drive and energy to wander, engage in destructive behaviour, and to ingest inedible objects. Although psychotropics may have a place in the treatment of challenging behaviours in persons with

ID, the scientific basis for prescribing antipsychotics to persons with ID and pica has not been established. Better evidence of the efficacy of antipsychotic medication for treating pica is needed in order to guide appropriate management practices for pica. Recently, Schneider, Tariot, Dagerman, Davis, Hsiao, Ismail et al. (2006) examined the efficacy of atypical antipsychotics for reducing problem behaviours in persons with Alzheimer's disease using a double-blind, placebo-controlled trail. They found that atypical antipsychotics produced little clinical benefit and more adverse effects compared to placebo, supporting the notion that antipsychotics should be used cautiously in the treatment of behaviour problems.

Potential Consequences of Pica

An important finding was that pica appeared to be related to negative quality of life outcomes. The presence of pica was significantly associated with the absence of strong and supportive relationship with family and social contact after adjusting for other factors. Persons with pica were also placed out of their family home at a younger age suggesting that they were difficult to manage and that the family was advised by physicians or others to place them in an institution at an early age. There may be a number of reasons for the lack of involvement of family in their lives. First, physical distance—persons with pica may have initially been moved to an institution that was far away from their family and with time family got used to not keeping in contact. Second, pica behaviour is difficult to manage and as such may be overwhelming and distressful for family members to visit them. Third, families may have been discouraged to visit them in the institutions because of the limited interactions they could have with their family member (unable to take them out into the community) or the emotional reaction they had when visiting them in a ward type setting (pica wards). Lastly, persons with pica in this sample were on average in their early fifties and mostly likely have aging or deceased parents. As such, the family responsible for visiting would be a younger generation, possibly siblings, who may not feel as compelled to keep in touch with them. In summary, pica has a significant impact on family relationships, with few having a family member visiting them or actively taking part in their lives. Thus, persons with pica are dependent on formal supports (i.e., paid staff) with respect to social and emotional support.

Multivariate analysis also revealed that pica was related to the absence of participation in social and recreational activities. These results suggest that persons with pica may be excluded or hindered from activities due to safety concerns or inadequate staff support in activities. For example, a lower proportion of adults with pica engaged in arts and crafts probably because of the worry that they would ingest the supplies for the activity (e.g., paper, glue, markers, etc). Staff are also likely to be selective in the kinds of activities that they allow persons with pica to participate in to prevent ingestion of inedibles. Involvement in activities for persons with pica is also likely to be dependent on the availability of staff supervision. As indicated previously, individuals with pica require more intensive supervision and probably more so for activity involvement and thus the staffing levels may not be available in the facilities.

Absence of association between gastrointestinal symptoms and pica was unexpected given that previous research has reported that persons with pica suffer from more medical complications, particularly GI symptoms. This finding implies that persons with pica are being effectively managed in the facilities and therefore few individuals have the opportunity to successfully ingest inedibles to cause medical complications. It could also be argued that gastrointestinal symptoms are difficult to detect in persons with pica because they are non-verbal and unable to articulate their health symptoms.

Conclusions

In summary, this study suggests that persons with pica show some unique characteristics and have a tendency toward requiring more intensive supervision. Pica was also shown to be linked to negative social outcomes and reduced activity involvement. A more diverse sample of persons with ID (e.g., greater range of levels of ID, and ID syndromes) in the community will allow for further investigation of the characteristics associated with pica and allow for more precise estimates of these characteristics.

Limitations of the Study

There are several limitations in this study that should be noted. First, the sample of community-dwelling adults with ID represents a convenience sample (Martin, 2004), and therefore it may not be representative of this population in general. In contrast, the facility sample of adults with ID constitutes a census sample and as such, these results are generalizable to adults with ID in Ontario's facilities. A second limitation is that the study is cross-sectional, and thus variables identified as risk factors for pica are essentially correlates of pica since it is not possible to discern the temporal sequence of predictor variables in relation to pica. Individuals with pica probably show a wide variation in duration of the disorder, and thus, the present cross-sectional study has an inherent selection bias such that it captures individuals with pica who represent chronic cases/survivors of pica. Third, analyses was based on secondary analysis of data developed for other purposes and thus study variables may not be specific enough to give detailed analysis of the phenomenon of pica, and thus certain clinical issues cannot be addressed here. For instance, information on the types of in-edible objects consumed, blood levels of iron and zinc, restraint use, or specific medications prescribed to treat pica were not measured. Fourth, due to the small sample size of individuals with pica in the community (n=14), statistical analyses was confined to the facility sample.

Future Research

Additional research will be necessary to confirm the results of this study and to extend them in various ways, including ones that might shed light on the development and maintenance of pica across the lifespan. With respect to confirming the findings of this study, it would be desirable to establish their generalizability by replicating them with different age groups of persons with ID, using a large community sample.

Most research has been mainly concerned with the documenting the prevalence of pica, and to a lesser extent exploring the etiology of pica. Future research should concentrate more exclusively on the causal pathways of pica using prospective longitudinal methods to determine factors that precede the development of pica, and also the factors that maintain the behaviour over the lifespan in individuals with ID. A particularly important area of future research lies in studying which interventions or combination of interventions are useful in reducing or eliminating pica, as there is a scarcity of evidence on what works and does not work among researchers and front-line workers. In view of the present findings, it might be useful to see whether communication and sensory interventions might reduce pica. Some preliminary work has been done, with some positive results, though these often were single case studies with short-term follow-up. Longitudinal studies will need to be conducted with long term follow-up in order to assess the real-world applicability of these interventions. It is important that researchers and clinicians report null findings; that is, treatment failures so that this knowledge is disseminated to key stakeholders, including direct support staff and families as they often are the ones who implement the strategies. Finally, empirical studies are needed to determine whether less intrusive procedures are more effective at reducing pica than more intrusive ones. To date, no one has empirically examined whether increased supervision and environmental controls are equally or more effective at managing pica compared to the use of more restrictive procedures, like mechanical restraints or medication. This has implications for increased quality of life for persons with pica.

7.0 Implications for Policy and Practice

The implications regarding supporting individuals with pica in the community, as well as more effective ways for allocating resources to meet the high resource needs of persons with pica will be discussed.

It was found that pica was quite common in Ontario's facilities and was infrequent in our community sample. With the mandate to close the remaining facilities in Ontario by March, 2009, an influx of persons with pica will need to be supported in the community. Community agencies will need additional resources to meet the distinct needs of this sub-population with respect to education and training for its staff, and additional funding for appropriate levels of staffing. Moreover, community homes may need to be modified to ensure a safe environment for those with pica. Decisions will also need to be made regarding the appropriate placement of persons with pica; in other words, should persons with pica reside with others with pica or those without. Community agencies will also need to be able to access specialized support services, such as psychologists, behavioural therapists, speech-language therapists, and occupational therapists to help them manage pica. The MCSS is planning to enhance these services for persons with dual diagnosis (intellectual disability and a mental health issue/challenging behaviours) with the creation of four community networks of specialized care in Ontario (MCSS, 2005).

A key finding was that pica was related to higher levels of staff supervision. This reflects the fact that persons with pica need constant monitoring or supervision to prevent the risk ingestion of items and in turn its health consequences. With this in mind, the MCSS should consider changing the way it allocates funding to persons with ID to ensure that particular subgroups of high-need clients have adequate supports. Currently, the MCSS allocates funding to developmental service agencies for residential and vocational programs rather than according to individual need (Pedlar, Hutchison, Arai, Dunn, 2000). The MCSS is also known to provide additional funding for those with specific needs to agencies, although this currently is not a systematic approach. We propose that the MCSS develop a funding system that allocates funding based on personal characteristics that are linked to resource intensity. This concept is referred to as a case-mix—a funding system which allocates resources based on client characteristics, taking into account functional, behavioural, and medical aspects (Fries, Schneider, Foley, Garazzi, Burke, & Cornelius, 1994; Hirdes, Fries, Botz, Ensley, Marhaba, & Perez, 2003). Other sectors have applied the case-mix approach to funding, including long-term care and in-patient psychiatry. A case-mix system will allow the MCSS to effectively plan and provide adequate supports to subgroups of individuals with higher, more complex needs. Staffing levels is also a very important issue concerning the effective management of pica in the community. The provision of more intensive staffing for persons with pica in community will not only mange pica effectively, but may improve their quality of life. Intensive staffing may allow persons with pica to engage in more meaningful social and recreational activities, and may also reduce inappropriate pharmacological treatment.

Caregivers and clinical professionals should be made aware of the risk factors of pica and the complexities of supporting individuals with pica. First, education should focus on the fact that persons with relatively severe cognitive impairment, who are non-verbal, and those with autism are at greatest risk. This may aid in prevention and early identification of pica as it may go unnoticed if it is a covert behaviour and allow for more immediate intervention. Second, education should emphasize that persons with pica are at particular risk for social isolation and reduced engagement in activities. To address these issues, a wide variety of activity interventions should be provided to individuals with pica alongside behaviour management. For example, snoezelen, swimming, pet therapy, and other preferred activities may meet the sensory stimulation needs of adults with pica rather than passive activities such as watching TV and listening to the radio (the most frequently reported activities). Interventions that focus on enhancing communication among persons with pica may also be beneficial—techniques such as picture exchange and gestures may help individuals communicate their needs and desires more effectively and enhance social engagement and may concurrently reduce the likelihood of pica. Staff should also consider that pica may constitute a major source of stress for family. Thus, families also need education and support. Caregivers as well as health and clinical professions should also be informed on the use and misuse of psychotropic medication such as antipsychotics for challenging behaviours.

A final recommendation is that a clinical assessment protocol (CAP) be developed specifically for pica to enhance the support planning applications of the inter*RAI* ID. The objective of the pica CAP would not only be to alert caregivers to the health risks and social consequences of pica, but more importantly it would provide comprehensive guidelines for developing a behavioural support plan for the management of pica. For example, the protocol would encourage caregivers to assess the function of the behaviour, suggest approaches to manage the behaviour based on the current literature, and also provide a listing of community clinical networks to contact if further evaluation and support is needed. In summary, the pica CAP will encourage caregivers to conduct a more in-depth evaluation of pica in order to better understand and manage the behaviour.

8.0 Qualitative Methods

In the second phase of this research, the perspectives of direct-care staff from facility and community-based settings were examined. The objective of this qualitative study was to gain a more detailed understanding of the support practices of staff in the management of pica. Of particular interest was on examination of the strategies found to be beneficial in the management of pica. The following section provides a description of the qualitative methods, the major themes that emerged across the focus groups, and how these themes inform policy and practice.

8.1 Purpose

The purpose of this study was to develop an understanding of the support needs of adults with ID and pica in facility[1] and community-based services from a support worker's perspective. Qualitative methods were used to deepen our understanding of supporting someone with pica. The complexity of the disability means that in large part the researcher needs to rely on the support worker's perceptions in order to capture the needs of persons with pica. The provision of effective support for persons with pica is a significant issue facing community services in Ontario, particularly following the closure of the three facilities and less certainty around the availability of community support for persons with intellectual disabilities.

8.2 Research Questions

Questions focused on the experiences of staff in supporting individuals with ID and pica, so that they could identify strategies that are beneficial in managing pica, and the impact of pica on the quality of life of persons with pica and others. Also, the study sought to find out what

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[1] In recognition of using the terminology of the participants, the term "facility" is used instead of "institution"

additional resources were needed in order to meet the support needs of persons with pica more effectively in the community.

The central question for this study was:

1. According to a staff's perspective, what are the support needs of adults with ID and pica in community and facility settings?

The eight questions that follow were used to tap into the various aspects of supporting an individual with pica:

i. What is it like to support someone with pica?
ii. How much time is involved in supporting someone with pica?
iii. What strategies work well in managing pica?
iv. What strategies do not work well in managing pica?
v. What resources do you use right now to help you deal with pica?
vi. What resources would be helpful?
vii. What challenges or barriers make it difficult to manage and/or reduce pica?
viii. Overall, how does pica affect you as a caregiver? Also, how does it affect other staff members, family, and housemates?

An interview guide containing these key questions and sub-questions and probes was developed to facilitate the discussion in the focus group setting used to gather data in response to these questions (See Appendix D).

8.3 Data collection

8.3.1 Purposive sampling

Using purposive sampling, direct-care staff with experience providing support to adults with ID and pica in the community and facility setting were recruited. To obtain participants, contact was made through information letters (Appendix E) and telephone calls with various community developmental service agencies and Huronia Regional Centre (HRC) that support individuals with ID. Specifically, staff were sought who supported an individual or individuals with the following three characteristics: has an intellectual disability, is 18 years or older, and has exhibited pica in the last year. The person must have displayed pica in the last year in order for the disability to be clinically relevant and a current support issue that is being managed by staff.

Follow-up telephone calls were made one week after the information letters were mailed or emailed (Appendix F). At this time, the researcher asked the staff whether they were interested in participating, reiterated the purpose of the study and answered any questions that the staff member may have had. If a staff member was interested, a time was arranged and the expectations of the focus group were clarified, including the length of time that the focus group would require and the importance of audiotaping in terms of capturing accurate information. The researcher then contacted each staff member two days before the focus group to confirm the date and time of the focus group.

8.3.2 Recruitment and Focus Group Procedures

Two focus groups served as the data collection method. The community and facility focus group were conducted separately. A total of six staff participated in the community focus group and four staff in the facility focus group. The community focus group was held at the University of Waterloo, in Waterloo, Ontario. The facility focus group took place at the HRC in Orillia, Ontario. Participants attended a two- to two and a half hour focus group. The participants received an information letter about the purpose of the study and the focus group questions in advance. As well, each participant was asked to fill out a brief background questionnaire to obtain basic demographic information prior to the focus group (See Appendix G). At the beginning of the session, participants read and signed a consent form (Appendix H). A semi-structured focus group interview guide was used to provide general direction for the focus group discussions (See Appendix D). Although these questions were determined in advance, the researcher had the flexibility to question and probe ideas that arose, using a conversational style.

The community focus group was conducted using a two-team approach consisting of a moderator and an assistant moderator (an undergraduate student). As a moderator, the researcher’s role was to lead the focus group discussions and to keep the conversation flowing. The assistant moderator was responsible for taking comprehensive notes, and handled the logistics of the focus group (i.e., operating the tape recorder, environmental conditions, and refreshments). Descriptive notes were also recorded, including the names, as well as facial expressions and body language of the participants by the assistant moderator. Non-verbal description aided in the interpretation of the data, specifically because it added emphasis to a viewpoint (e.g., head nodding, facial expressions) to indicate a person’s agreement or support, or it indicated a person’s disagreement (head shaking, less eye contact) regarding specific issues which may not have been captured on the recording. In other words, field notes helped the researcher to identify how the participants initially reacted to the questions and how they felt about other participants’ opinions. The researcher and assistant moderator debriefed and reflective notes were taken after the focus group session to record first impressions, thoughts, and feelings regarding the focus group. Having an assistant moderator should increase the amount and accuracy of the information collected and the rigor of the analysis.

The facility focus group was conducted solely by the primary researcher. However, both focus groups were audio-taped for transcription to ensure that what was being said by the participants was being recorded accurately and to ensure that the researcher could focus on the discussion.

8.3.3 Role of the Researcher

Given that the researcher is regarded as the research instrument for collecting and developing ideas embedded in the data, it is important to make transparent the assumptions and biases that he/she brings to the qualitative process; these assumptions are often referred to as “experiential data”. In addition, the researcher will carry into the research activity “sensitizing concepts” which are drawn from exposure to relevant literature (Patton, 2002). The researcher has five years of personal experience as a front-line support worker for persons with ID with K-W Habilitation Services and K-W Extend-A-Family, though she has not specifically supported persons with pica. As such, the researcher has familiarity with the field and brings experiential data (Blumer, 1978) to the study, such as the vocabulary, terms, and support practices that are specific to supporting persons with ID. In terms of theoretical sensitivity, the researcher had conducted a literature review on the topic of pica in persons with ID prior to conducting the focus groups and consequently developed certain perceptions and ideas on the topic that directed and influenced her analysis. Specifically, the researcher had notions that pica was related to gender (males), the severity of the person’s cognitive impairment, and particular ID syndromes such as autism and Prader-Willi syndrome. Moreover, the researcher had gleaned from the literature that pica was difficult to manage and was associated with other challenging behaviours such as aggression and thus intrusive techniques have been typically employed such as protective equipment, restraints, and medications. The researcher suspected that persons with pica would require constant monitoring because of the physical complications that can arise from it. As well, persons with pica may be perceived negatively by others, including family members and staff because of the types of substances they ingest (such as feces, dirt).

8.3.4 Analysis

In this study, constant comparison occurred during data collection and throughout analysis. Although utilized data analysis techniques commonly employed in grounded theory, this research does not constitute a grounded theory study. The researcher had conducted a literature review first, formulated an hypothesis in advance that persons with pica require greater resources relative to others with ID without pica. In addition, the small sample size (and non-theoretical sampling), and time constraints, all minimized the possibility that the researcher would be able to conduct true grounded theory. In fact, the conclusions that will be drawn will be predominantly descriptive in nature, rather than theoretical. Therefore, the aim of the present analysis was to gather rich description from the staff about their experiences of supporting persons with ID and pica rather than developing a general theory.

The interviews were transcribed verbatim and coded to develop themes or categories. The transcripts were analyzed using two coding strategies: open and axial coding (Strauss, 1987). Open coding was used initially and involved line-by-line coding of the text to generate provisional categories and concepts. Axial coding was then used to develop particular categories and sub-categories, and then making connections between them. Coding ceased when theoretical saturation had been reached. As suggested above, throughout the above coding process, the constant comparison method was employed. The researcher constantly compared the data on several different levels including the comparison of categories and themes, responses between participants, and the comparison of responses across the two different settings (two focus groups). These constant comparisons involved the modification, and fine tuning of the categories and themes. Memoing and diagramming were also used throughout the course of the analysis in order to record any hunches, and ideas that came to mind regarding the categories and their relationships; this led to more abstract thinking about the data. Diagrams also aided the researcher in visualizing the relationships between the different categories (Kirby & McKenna; Miles & Huberman, 1994; Patton, 2002). Final data analysis involved the interpretation of the patterns and themes.

8.3.5 Credibility

The conventional criteria for establishing the validity of a study has come under scrutiny in recent years with the acknowledgement that both quantitative and qualitative methods have their strengths and weaknesses. As Richardson (2000) posits, truth can be thought of as a crystal that has multiple dimensions or angles. To this end, crystallization employing multiple methods and perspectives is accepted and thus the knowledge that is generated from this study, although offering a partial understanding of the phenomenon is regarded as a valid perspective. A number of techniques within this paradigm will be used to increase the rigor of the study's findings.

The credibility of the data was established by the inclusion of a variety of data sources (triangulation of data sources), such as focus group data, as well as descriptive, reflective, and analytic notes (memos), which will allow the consistency of the findings to be verified. Alternative explanations or categories were also be followed up and considered. If no evidence was found to support the alternative explanations, this buttressed the original explanation provided by the researcher. In addition, the researcher also looked for, reported, and explained negative cases (deviant cases), or cases that did not fit with the established coding (Patton, 2002). Random checks of the data were performed by a second researcher (an undergrad student) in order to verify the coding scheme. Finally, member checks were conducted, that is, participants were asked to verify the accuracy of the findings and interpretations that emerged from the data (Patton, 2002). In practical terms, this process involved providing an executive summary of the main findings and themes to the participants and asking them to provide their feedback on them (See Appendix I). Participants were asked to phone, mail, or email their feedback to the researcher. The majority of participants indicated that they agreed with the final themes—all eight staff that responded agreed that the themes and interpretations accurately reflected their situation. There were two non-respondents. A few staff took the opportunity to provide more information on their particular perspectives on various issues, including two staff emphasized that other staff and the community needed more education and training on pica. Another staff emphasized the need for others to understand that in some cases the severity of the pica warrants intrusive measures to protect the person’s safety.

9.0 Qualitative Findings

9.1 Introduction

Findings from the focus groups are presented in this section. This section will describe the composition of the participants for each focus group and present the main themes that emerged across the groups**.** The findings are grounded in the staff's thoughts, stories, and opinions. Direct quotations are included to illustrate the themes. To preserve the anonymity of the participants, names are removed. Discussion and conclusions of the main themes will be examined in detail in sections 10.0 and 11.0.

9.2 Description of Study Participants

9.2.1 Facility Focus Group

The facility focus group was conducted with four staff from the Huronia Regional Centre (HRC). The participants consisted of four men who had been working at HRC on average for 23.8 years (range of 19 to 29 years), and had extensive front-line experience supporting individuals with pica. They provided a wide range of supports to persons with pica, including direct day-to-day care of persons with pica, training of staff, and the development of protocols to create pica-friendly environments for their residents. Also, some staff provided more indirect support such as developing intervention plans with staff; reviewing interventions every six to twelve months; monitoring the use of interventions such as mechanical restraints; and training staff with regard to the management of pica. Three of the four staff did not have any previous experience supporting persons with pica prior to working at HRC.

9.2.2 Community Focus Group

A total of six front-line staff from four community agencies in southwestern Ontario participated in the focus group. Five of the six participants were female and one participant was male. All participants were full-time residential counselors and responsible for the day-to-day support of persons with ID, including personal care, recreation, medical appointments, and managing finances. Three of the participants had had prior experience supporting an individual with pica at a different support job. Overall, staff from the community had been supporting persons with pica on average for 5 years (range 3 to 8 years).

9.3 Overview of Findings

The transcripts were analyzed thematically and grouped into six themes. The following themes were identified. Each of these is discussed in more detail below.

1. Prevention
2. Knowing the individual
3. Support Network
4. Lack of Knowledge
5. Inadequate Staff Support
6. Functioning Level of the Individual

9.4 Prevention

There were a variety of ways in which staff managed pica behaviour, but the most consistently reported approach was prevention. Prevention centers on the provision of environmental controls, staff monitoring, and alternative activities.

9.4.1 Environmental Controls

A major concern for staff is ensuring that the individuals that they support do not have opportunities to ingest anything in their environment. This means that staff keep the living environment clean of inedibles by locking up cupboards, drawers, and rooms, sweeping floors and cleaning up after themselves. Commonly, individuals with pica do not have access to personal belongings nor do they have mattress covers, bedding, and pillows because of the risk of ingestion. By concentrating efforts on providing a pica-friendly environment, the staff do not have to resort to more intrusive strategies. A staff at HRC supported this notion by stating:

> "I'd say we've gotten rid of three quarters of the restraint use for pica just through prevention"

Half of the community staff felt strongly that environmental controls are the only effective means of managing pica. This point is reiterated by one staff:

> "We just try and keep things out of reach. That's the best we can do."

In both the community and the facility, cleaning routines were put into place to keep the environment "pica-friendly" and took up a significant portion of the staff's time. These routines are more rigorous in the facility and are formally called "pica sweeps." Pica sweeps are completed and documented on an hourly basis by staff to keep the living environment free from inedibles. This involves looking for and disposing of potential pica items such as small objects, threads, lint, plastic, garbage bags, rubber gloves, etc. In addition, the floors are swept with a dry dust mop. Although keeping the environment clean helps to reduce the risk of individuals obtaining and ingesting items, pica sweeps remain time-intensive for staff in the facility. As one facility staff noted:

> "The pica sweeps are there so in all fairness we are spending 24 hours a day watching…If you're outside and coming back in , they have to be checked to make sure they aren't bringing in foreign objects that can be used as pica material too. So, it's full time."

A similar experience was also related by community staff:

> "The majority of staff continue to look throughout their eight hour shift in the evening walking up and down making sure cupboards are locked, making sure there's no garbage cans, sweeping up floors, because we do have a number of people that will eat things off the floor. So basically it's an all night thing, that you're going back and forth just watching, making sure."

These pica-proofing routines appeared to be internalized by staff. For example, concerns about the person's safety were always present in the staff's mind during, and often times after, their shift. Two staff explained their experience:

> Staff 1:
> "You worry. You constantly double guess, did I lock all the cupboards? Did I check you know, under his bed? You know, and if he's already gone to bed, it's like, oh man he's already gone to bed. I can't go and check under his bed now. So your head's wondering, did you do everything you needed to do in order to try and keep him safe? And then you make sure you reiterate that to the staff that are coming in."
>
> Staff 2:
> "I would have to agree with that. You're always worrying. It's frustrating because you, even when you are at home, oh my god, did I leave the closed door really tight closed? Did I check under his bed? Oh I forgot to check under his bed. So you are always worrying about that."

These quotes illustrate how pica proofing becomes an automatic routine, constantly present in the staff's mind. Initially, of course, staff need to be trained on specific protocols, but with experience these protocols are cognitively reinforced, effectively increasing staff's vigilance.

Staff from HRC indicated that tailoring their residential environments to be pica friendly was expensive. Due to the large numbers of residents with pica at HRC and the severity of pica, many environments have been modified to be pica-friendly. In contrast, the staff from the community did not mention that cost is a factor in maintaining a pica-friendly environment. At HRC, they alter the living environments in a variety of ways to reduce the risk of pica. These range from the removal of all inedibles, to the provision of specialized furnishings that are difficult to rip or tear apart, to putting metal around the edges of doors and windowsills. Even the walls are protected with a special surface coating, called wall cladding, which makes the dry wall inaccessible. As well, unrippable mattress covers are used. Clothing is modified for some individuals so that they are unable to rip or tear their clothing and in some cases individuals wear one-piece jumpsuits (for those who ingest their diaper/underwear). Costs are also compounded by the fact that pica residents are often destructive in their environment. The following excerpt of dialogue illustrates this point:

> Staff 1:
> “The other thing that goes along with pica, with the developmental level is that you have a lot of destruction of property and the environment, so that creates more pica items which feeds into the other.”
>
> Staff 2:
> “Yeah, I mean, not to be financially driven, but the cost of replacing items and the cost of making the environment safe certainly has added to the bills here for the different things that we do.”

9.4.2 Alternative Activities

Keeping individuals occupied and engaged in alternative activities is another tool that staff find helpful in preventing the occurrence of pica. The majority of staff in both settings spoke of providing safe toys for the individuals to occupy themselves with. The staff from HRC mentioned that toys are particularly useful because they keep the individuals’ hands occupied and therefore reduce the likelihood of them scavenging for items and/or destroying items. Similarly, engagement in activities that the person enjoys reduces pica. One staff provided an illustration of how important it is to continue to allow the individual to engage in preferred activities, particularly on their good days (when there is a reduction in pica). He describes how incorporating preferred outings into the intervention plan as a reward was effective:

> “You get to know the person and know what they like and dislike. And if you know like say if he likes ice cream or again, if he likes going to the fire department or the Special Olympics. I mean you know he’s having a good day and you continue to reinforce that and say, “You know, you had a great day so we’re going to go sit on the fire truck”…And then if he does something [eats an inedible] and he’s out of there right away…You know I took him out of the environment. And eventually because he really wanted to be there, he would not eat items.”

In summary, prevention in the form of environmental controls proved to be the predominant strategy for managing pica. Routines to keep the environment clean were time-intensive and internalized by staff. As well, creating and maintaining pica friendly living environments was reported to be costly by staff at HRC. Lastly, keeping individuals stimulated with toys or other activities prevents pica. Taken together, staff in both settings agreed that prevention was the most effective way of reducing the likelihood of pica behaviour.

9.5 Knowing the Individual

Staff's familiarity with the individual they support is another important factor that is helpful in managing pica. By having knowledge about each individual, staff stated they felt more able to prevent and manage pica. Knowing the individual is central in three main aspects: knowing the desired items that they prefer, knowing the severity of the pica, and knowing that each individual is unique with respect to treatment.

9.5.1 Types of items ingested

A common theme that emerged from the focus groups was that individuals with pica are unique in their choice of pica items, with some preferring specific items while others are completely indiscriminate. Awareness of the preferred items that the individuals ingest is a helpful tool for staff in reducing the risk of pica. Staff at HRC have developed behaviour intervention plans that document the preferred pica items for each of their residents, which in turn increases staff's awareness. One staff summed it up as follows:

> "Through our behavioural consultants we develop protocols for each and every resident…We have a list of materials that need to be checked for, and the residents' names are placed on there, and like [another staff] said, so anybody new coming into the area itself can just quickly review and pinpoint what they need to be looking for during the pica sweeps."

In the community, information about the preferred pica items of the residents is relayed through the individual's information binders, and staff stay informed through staff meetings.

9.5.2 Severity of Pica

The stories from the staff also revealed that pica ranges in frequency and severity. This was emphasized by staff from HRC:

> "I mean different residents have different levels of pica. I mean some of our individuals liked cigarette butts...they would go through a brick wall to get to them where other people are very passive about it. So I think that also it depends upon the type of resident you have because some people are, I mean, it's their number one mission from the time they get up in the morning."

Similarly, staff from the community noted differences in the motivation and energy persons have for engaging in the behaviour. One staff commented:

> "The woman I support is very mild I guess compared to everyone else and it is mostly food that she goes after although you know, there's been the bar of soap, the earrings, and one day I found a staple in her teeth. But she is very lazy, so she won't bend really to find something…Like it doesn't matter that we have garbage cans or things like that because she won't bend down, so it has to be very easily accessible to her for her to ingest."

Some individuals in the community display severe pica and as a result more intrusive methods are employed to manage their behaviour. Here is a story from one community staff:

> "Now one of our individuals wears a helmet. He had to because he's had three surgeries already. He was ingesting nails and from the windows he was literally just taking the wood around it and eating it, so it was really bad. So now he wears a helmet. He asks us to put his helmet on. He knows that's what he needs."

The use of mechanical restraints was more prevalent in the facility, including mitts with paddles, splints for the arms, and helmets with a face mask. The first two restraints mechanically prevent the individual from grasping items to put in their mouths, while helmets with a face mask prevent the individual from swallowing inedibles. While many community staff were surprised by the use of a helmet for an individual in the community and felt it to be an extreme method, this attitude may reflect the relative infrequency of severe cases of pica in the community.

Along these same lines, all the staff at HRC were very aware that mechanical restraints are an intrusive measure for managing pica. However, they stressed that mechanical restraints are generally used for individuals with severe pica and those who have had medical complications that have resulted in surgeries. Thus, once medical complications have occurred in an individual, it becomes increasingly important for staff to prevent pica because of the health and mortality risks associated with further obstructions.

> “We’ve had people that have ingested some things that have required some pretty invasive surgeries. We have a number of residents who, I mean, I don’t think there’s a magic number, they [health professionals] say they can’t have anymore surgeries. So we have to be extremely diligent with those people because their systems cannot handle so to speak another surgery. So a bad day really is if somebody does ingest something. That’s sort of the ultimate bad day.”

A community staff also expressed the reason why the individual she supports requires a mechanical restraint in the form of a helmet:

> Staff: “With one specific individual that we support, it (pica) almost cost him his life. One more surgery, that’s it for him”
>
> Researcher: “How many surgeries has he had?”
>
> Staff: “Three.”
>
> Researcher: “Three? To remove the foreign objects?”
>
> Staff: “Yeah. And pieces of his colon were perforated. And so that’s why this (helmet with a face mask) is a drastic measure but this is to save his life. So we can save lives.”

Although environmental controls reduce the likelihood of pica, some individuals still display the behaviour from time to time, while others display severe forms resulting in the implementation of additional strategies to protect the person's safety, such as mechanical restraints. Thus, strategies for reducing pica vary depending on the severity of the person's pica.

9.5.3 Diversity of Strategies

The techniques used to manage pica varied by setting and by staff. Despite this variation, the focus groups revealed that all the staff held one belief in common: strategies for reducing pica should be tailored to the individual. Attempts should be made by staff and other professionals to find out what works and does not work for each individual; in other words, no single approach emerged as being effective across the cross-section of individuals supported by focus group participants.

For example, there was mixed opinion on whether medication was a useful strategy for managing pica. One staff reported that a low dose of zyprexa, an antipsychotic medication, was effective at reducing pica in the individual she supported to almost zero levels. It was felt that anxiety was a cause of the person's pica. By contrast, another staff stated that antipsychotic medication had no effect on pica in the individuals that she supported. Likewise, all the staff from the facility strongly felt that medication was not effective in reducing pica incidents. In the words of one staff at HRC:

> "I think our psychiatrist has used different medications to see if it was like an obsessive-compulsive behaviour. But I don't think with much success…I think pica is more developmental than it's any sort of a mental health issue."

The individualized approach to managing pica was also reflected in the different types of alternative stimulation used to keep the individual occupied. In two separate instances, a rocking chair was used as a strategy to lessen a person’s anxiety and to provide stimulation; however, this approach continues to be effective for only one of the individuals. The other individual has come to perceive the rocking chair as a form of punishment:

> “He refuses to sit in his rocking chair. He thinks even like eight years later it’s a punishment. He won’t sit in it. So, I think that redirecting to one specific area is definitely not good.”

Similarly, the provision of alternative, edible substances may be effective in one case but not in another:

> Staff 1:
> “I’m thinking back to when we talked about replacing inedibles with edibles, like the popcorn and the cheesies. So that, did it work or didn’t or?”
>
> Staff 2**:**
> “I think it worked for some residents, the popcorn in particular seemed to work up in the Pad Three for some of those gentlemen. It doesn’t work across the board. I think that’s another thing we’ve learned is that you have to go by the individual resident.”

In summary, the above experiences indicated that staff perceived that only individual-based solutions work for persons with pica. Many expressed that this involved taking into account the individuals needs and preferences.

9.6 Support Network

Another factor identified by staff to be helpful in managing pica was having a good support network. “Support network” refers to the group of family, staff, and professionals that are responsible for the individuals’ well-being. Specifically, access to health and clinical supports and staff consistency were identified.

9.6.1 Access to Professional Supports

Professional support was variable between settings and across community agencies. The facility has a comprehensive team of professionals on-site including behavioural consultants, physicians, nurses, occupational therapists, kinesiologists, a dietician, and a speech-language therapist, all of whom work collaboratively to provide individualized support. A psychiatrist also visits on the facility two or three times a month. The staff even reported that they have connections to specialized resources that are integral to providing pica-friendly clothing and environments:

> “It was our seamstress that came up with a number of different types of jumpsuits and mitts depending on the client. Because we would have ones that were taking apart the mitts. And she would have to come up with different padding for the mitts. Stuff like that. But having the availability of a seamstress on site to be able to come up with these ideas is beneficial to us.”
>
> “I guess, stretching it a little may be resources such as our company that produces moduform furniture, something that would not, you know we have to go outside the facility to get something like that. So that technically could be classified as an outside resource.”

Despite having access to the above supports, many staff at HRC believed that it was meeting together as a team, and sharing information that was the most beneficial in developing protocols and strategies for dealing with individual cases of pica.

In contrast, while the availability of health and clinical support varies across different community agencies, support from family members in the community is more prominent. Staff indicated that family involvement consists of social visits or taking their child home for an overnight stay, but rarely involves attending medical appointments or advocating for services. Staff perceived that keeping the families informed on the health and behavioural status of their child reinforced the mutually supportive relationship between staff and family.

A minority of community staff had sought support from specialized clinical services. One staff had accessed Regional Support Associates (RSA)—a multidisciplinary team of behavioural specialists that provide assessment, treatment, and training to individuals with ID—because of the severity of the pica they were dealing with. This organization aided in the implementation of an individualized intervention plan. With this extra support, the staff's team was able to try different approaches and train staff in a consistent manner. As a result of this collaborative effort, the person they supported has been pica free for nine months. However, when other staff were asked whether they would be interested in accessing specialized clinical support, the majority were not aware of such services, and others felt that they were able to handle the behaviour on their own. Here is an example:

> Researcher**: “**Would you consider contacting a behavioural therapist or you know, a psychologist? Are you interested in accessing professional help to make a behavioural plan or has that already happened?”
>
> Staff**:** “Not for my individual. Maybe a few months later when I find that he's eating a whole lot more… but for you guys, I can completely see why you went through RSA. If I had that [severity of pica], I probably would have gone through Regional Supports as well.”

Overall, community agencies were self-contained and as such were used to being self-sufficient in managing difficult behaviours. The above quote demonstrates that staff are willing to wait until the severity of the behaviour escalates before seeking professional expertise. This may contribute to the persistence of pica over time.

An additional difficulty is that the physicians themselves may not have adequate training for dealing with persons with ID, and may lack knowledge about the medical symptoms and the complications of pica. Half of the community staff encountered difficulties when dealing with physicians. These range from the physician being fearful of the person they support to an unwillingness to take staff's concerns seriously:

> Staff 1:
> "My client's doctor, he won't even get close to him because he grabs. And he said to me, and I've been with him probably 10 to 12 times to the doctor. And every single time the doctor looks at me and he said, "Have I told you that the first time that I met this gentleman, he grabbed me and pulled me to the floor?" Every single time. And I say, "Yes doctor, you told me, the last ten times I was here, you told me the same thing." So he won't even get close to him. So he won't even get in the room. He'll be in the hallway."
>
> Staff 2:
> "My client had contact edema and the doctor says to me, I brought her back for the third time, he goes, "You don't have any children or anything, do you?" I was like, "No." And he was like, "Oh. Well you don't seem like you have a lot to do with your time." Like I sit at home and make stuff up to bring her to the doctor."

On the other hand, staff reported that positive relationships with their physicians open gateways to extra referrals and medical services, including ultrasounds to monitor gastrointestinal blockages.

9.6.2 Staff Consistency

Staff consistency figured prominently in the staff's reflections on facilitating the management of pica in the community. A consistent approach to managing pica was facilitated by having good staff relations, good communication, and protocols in place.

There was a consensus among community staff that good relations among staff members in a group home is important to maintaining consistency in the home. A staff commented on his feelings about the importance of having a good team and developing good rapport:

> " I was just saying it all has to come together. I think you have to have a strong team. And I know we have a very strong team. There's guidelines, protocols you have to follow. And you have to be positive with the part-time staff too. You have to make them feel appreciated. We you know, have a staff meeting, I'll bring pizza or whatever you know. You know, pop. And then you all work as a team and if you don't work as a team, the pica, you always have it. And I think that's what made our situation get better because we have a strong team. And the consistency's so important. And without the consistency, it will never work."

Others commented on the importance of keeping staff long-term to assist in managing pica:

> "When they have the same people in their lives, it makes a big difference."

Half of the community staff reported that factors such as high staff turnover, and problems with part-time staff not following protocols or attending meetings hindered the development of a strong team and hence consistency in managing pica. In some instances, new staff left their jobs because they feared the individuals or had difficulties in managing their behaviour. As well, clashes between full-time and part-time staff became apparent in the discussion. Excerpts illustrating the lack of cohesion among full-time staff and part-time staff follow:

> "They [part-time staff] have their routines, and have their way of thinking. Like you come in and you're the foreigner on the weekends as the full-timer.

> Part-timers don’t have the responsibilities. So they only do the basics. They don’t follow instructions, they don’t want to bother with that. “Oh I’m just here for eight or sixteen hours on Saturday and Sunday, I don’t have to deal with this. You want to eat more than usual? Go for it. I’m not going to fight with you [the individual they support]. I’m only here for 16 hours, so let the full-timers deal with it. They make more money than us. They have benefits so I’m not going to worry about it.” I’ve heard those comments.”

One staff remarked that part-time staff often did not understand the dangers of pica. This may stem from poor training of part-time staff and the poor communication between full-time and part-time staff.

Staff in the facility, too, expressed that maintaining good working relationships with co-workers is integral. They all recognized that staff are different in their approaches to managing behaviour and often disagree. The facility remedied this problem by developing protocols that ensure that every staff is consistent in their approach to managing pica. The value of consistency was emphasized by two staff from HRC:

> Staff 1:
> “And consistency is probably one of the most important parts. That’s one of the main reasons we developed a protocol system, because if one staff had one feeling about something and I had another and another staff had a different one, well depending on who’s there, I may manage a behaviour in a different way. So we, and then lots of other reasons we found that we need to have consistency. So especially for pica, this way it lets everybody off the hook. Like [another staff] and I don’t have to get in to a disagreement about my approach versus his. Well he can just say, “You know what? Pay attention. It says so right here!” And really it does. That saves a lot of aggravation I think.”
>
> Staff 2:
> “I think the communication thing is so important to where again we have different people that work with the residents here. And some may devote a little more attention to noticing certain types of behaviours with the residents and we can sit back and we may get a difference of opinion. Like he says I don’t see this type of behaviour in a certain resident where somebody else may. So that has to be listed down on our protocol so everybody can say well the potential may be there depending on the circumstances and depending on who’s working that specific day or you know. So at least there is a plan in place where everybody can say, “Well I don’t see that but

> given a different type of environment or a different situation that comes up, it may exhibit itself." So we have to all be aware that this potentially could happen."

Overall, staff consistency emerged as an important aspect of managing pica. As noted by the staff, having good staff relations, and communication between staff in the form of protocols is beneficial. However, conflict between full-time and part-time staff and staff turnover reveals the often fragile nature of the support network for persons with ID and pica in the community.

9.7 Lack of Knowledge

A common thread among the responses of both community and facility staff was that there was a lack of knowledge among staff, family, and the community at large regarding the cause of pica and its treatment.

9.7.1 Staff

With the exception of a couple of staff in the community who were able to reduce or eliminate pica successfully, staff mentioned that they did not have enough information about pica and felt that the behaviour was intractable. A staff from HRC explained:

> "Because you know, we're all in this business because we want to do the very best for our residents and give them all the opportunities we can. And it's just, it's a very perplexing problem that we can't figure out how to change it. So when a family member comes to you, I mean it really puts you on the hot seat because they have very limited knowledge about why can't you change this behaviour. And that's tough, tough because so little is known about it that it's a tough thing to change…Yeah, I'm not sure that the resources are out there and again, pooling everybody's expertise and years of experience here, I feel quite confident that you know we're doing the best we can with what we have."

Another barrier is the scarcity of research on interventions for pica. One staff remarked:

> "I've checked the internet quite often and there's not a lot really that helps aside from what we already do in the way of prevention."

The following excerpt from the facility focus group further illustrates the lack of knowledge and frustration that staff feel:

> Staff 1: “I think a big barrier too is trying to understand the function of the behaviour. So I don’t know, it’s one of those things, I have yet to come up with anything that tells me why somebody exhibits pica.”
> Staff 2: “Or why this one is more severe than this one. There’s no guidelines, no set out criteria for us.”
> Staff 3: “It’s a pretty grey area still to this day.”

Other staff in the community noted that if they had examples of cases of pica that other people have dealt with it would be helpful for developing strategies to support their individual:

> “It would be helpful if we had more information about what pica is. What works for one individual might not work for another one. But is we had a hundred individual cases, from those hundred probably two or three would help my individual. So I would like more information, in the form of examples.”

Another community staff asserted that the lack of information sharing among staff from other agencies was a barrier to supporting people with pica. He felt that if this situation were remedied, he would not have to reinvent the wheel in terms of collecting information and developing guidelines and protocols:

> “If I had someone else’s little guide, it would have just made things so much easier. And all the information you kind of have to find out on your own. And it was difficult. It took a long time. If we would have had the information sooner, we maybe could have reduced the behaviour sooner, who knows.”

Lastly, lack of knowledge of available services and how to access them was a barrier for many staff. In fact, more than half of the staff in the community had no awareness of such services and thus had made no attempt at connecting with specialized clinical services to gain extra support for managing pica. As one staff put it:

> "At this time too we don't really have any community resources or anything so we haven't tried any of those things. I don't know. We haven't really had any other ideas to deal with it."

Therefore, staff need to be better educated about the service system and how to connect with the ministry to gain extra clinical support and access to knowledge and resources for the management of pica.

9.7.2 Family

Most support staff from both settings indicated that family members often lack an understanding of the difficulties in managing pica. This often led staff to feel that they were failing at their job. One staff reiterated this point:

> "We even had a parent say, "Well can't you give him a pill to make him stop." And you run into the problem where you don't feel you are doing your job or you're failing at your job you're doing. But once you get past that, it's more complacency and now we're used to it, that's just the way it is."

Staff from the facility reported that families also have difficulty accepting the limitations placed on their offspring's independence because of the danger that they will ingest items:

> "For family members it's tough to when they come to take their son or daughter and we have to say sorry you can't take them to McDonald's because you're going to run into big problems so that's hard on them. It's hard on us too."

A minority of community staff noted that parents were in denial that their child exhibited the behaviour. In one case, parents insisted that their child just collected and hid items rather than ingesting them, while another staff reported that a mother never spoke about her daughter's pica and never used the term "pica". The remaining staff in the community noted that family were very aware of pica and its consequences but were often afraid of it occurring during their supervision and lacked the knowledge and confidence to manage it on their own. Responses from both settings were consistent in the view that family often lack an understanding of pica and require reassurance and education about the difficulties of managing pica as well as strategies for managing the behaviour.

9.7.3 Community

A third major concern was the lack of knowledge and education about pica in the community. The majority of community staff expressed feelings of embarrassment about their client's public pica behaviour. It is not uncommon that staff are reluctant to take the individual out into the community because of the public response to the person's behaviour. One staff demonstrated this point and offered a possible solution:

> "The community was an issue with the individual going out to McDonald's or somewhere, embarrassing himself and the staff. Could be a 7-Eleven, wherever. Church was a big problem. He attends a Mennonite church and staff were having a hard time with the individual. So I thought I would write a note to everybody. They have little mailboxes and I put a little note saying, "Hello, my name is so-and-so and you know, I have this pica. And please excuse me. I may jump up in the middle of the ceremony and you know, bite a wall or something." And, the people then can accept it, because people didn't know, that's the thing…once people knew at church, they weren't awing and looking at him, it made the individual and the staff feel better."

One staff expressed dissatisfaction about how the public stared at the individual she supported due to the protective helmet that he wore:

> "It's not pleasant to have people staring at us because he's wearing a helmet. So find out why he's wearing a helmet. Don't just stare at him. Don't just point at him. Don't laugh at him. We've been really lucky when we take them to restaurants. But some restaurants, not the staff but the people eating, they look at us like we were something

> out of this world. And that feeling, I don't like it. And I'm pretty sure that they (individuals she supports) don't like either."

All community staff expressed the wish that the community should be educated on these matters in order to make staff and the individuals they support feel more comfortable and included in the community. In the words of one staff:

> "We need to educate and communicate with the community to let them know that it's not only people like us that live in this world."

Staff from the facility were predominantly concerned with visitors from the community who did not have knowledge of pica and its complications. Staff spoke of outside contractors, for example, who come to work at HRC and are unaware of pica and the importance of cleaning up after themselves and the potential consequences it has for the residents. This point is emphasized by the following account:

> "We had our flooring being done out in the hallway and the outside contractors don't understand. They're working away and they're working in the evenings to be less disruptive. But they had a pile of knives and exacto knives left out. Luckily the counselor was checking one of the residents with pica who had a package of exacto knives in their pocket that the flooring guys had left behind. They never even think, never check their tools when they left that day. It's just because they don't understand our residents."

In summary, lack of knowledge on the part of the community not only contributes to stigmatization of persons with ID and pica, but also reinforces the tendencies of staff to remain at home or to only go out on "safe" outings, such as familiar restaurants or parks, in order to avoid embarrassment or negative reactions from the public. This further keeps the individual from engaging with the immediate community and prevents the community's exposure to pica. As a result, individuals with pica are essentially a hidden population. Education about pica is also important for those in the community, for example trades people and professionals, who come into contact with homes that support individuals with pica so that they are aware of the health risks associated with leaving items out.

9.8 Inadequate Staff Support

Inadequate staffing was one of the most important themes that emerged from the focus groups. In particular, this rang true for the staff at the facility. Adequate staff supervision appeared to be a key ingredient not only in managing pica successfully but also in terms of allowing individuals with pica to participate in meaningful activities and community outings. In this section, I will provide the staff to client ratios for each setting and discuss the social consequences of inadequate supervision, as well as consider other factors that make supervision an important factor in the management of pica.

9.8.1 Staff to Client Ratios

The staff to client ratio differed between facility and community based services. The HRC had a staff to client ratio of 2 staff per 8 residents. In the community, the staff to client ratio varied considerably across different agencies and group home settings. One staff worked in a large group home residence that supported 25 individuals with 6 staff. This translates to an estimated staff-to-client ratio of 2:8.3 persons, similar to the ratio at HRC. The remaining staff-to-client ratios ranged from 2:3 to 2:6. It is important to note, however, that the community ratios represent the maximum staff-to-client ratio during a shift, as staff numbers decline depending on the time of day (e.g., overnight shift). In general the staff-to-client ratio was smaller in the facility than in the community, with the exception of one residence in the community.

9.8.2 Consequences of Inadequate Staff Support

Due to the large numbers of individuals with pica at HRC and relatively fewer numbers of staff, a collective approach to managing pica was used instead of individually based solutions. In other words, lack of appropriate staffing made it difficult for the staff to develop and implement strategies that are specific to each individual. Thus, efforts were focused on maintaining a pica-friendly environment. Staff at the facility had attempted to implement individualized strategies in the past, but this often had negative implications for the other residents with pica behaviours:

> "One of our individuals was very driven to eat cigarette butts. And he also liked to hang on to certain types of things so we tried some, some hard safe toys to play with and keep his hands occupied. And we found that the only thing he really enjoyed hanging on to was branches and stuff like that. So we got the idea that we'd let him try to have a branch and hold on to it and that would distract him from the pica. Unfortunately, over time the branch breaks down and it left inedibles on the floor so some of our other residents decided to help themselves to that."

The majority of the staff from HRC also noted that inadequate staffing levels meant that individuals with pica were often excluded from activities:

> Staff 1: "We have to prioritize safety over other things. I mean we have a specific resident that I'm thinking of who, you know, loves to be on the swing all day but he also has very severe pica. And we have a beautiful campsite here that we attend during the summer time and just because of our staffing levels and stuff he's too volatile to go down to that area because it's not protected like here on site…So he has to stay back so we can provide care for you know, the 18 other individuals. So our priority is the 18 guys, trying to provide them with what we can as opposed to the one guy we can't."
>
> "I mean another example is a case where one fellow who loves to go out simply on a bus ride but takes the opportunity when on the bus, will scavenge along the floor of the bus to ingest things like that. So depending on the familiarity with the staffing and the staffing levels, perhaps one day when we're scheduled for a plain bus ride you know, he may have to be excluded because of this behaviour."
>
> Staff 2: "I think too they certainly lose any type of freedom or independence because even though the yard itself may be very safe as far as fencing so they wouldn't elope or get lost, they still just couldn't go out on the road. They just can't have fun in the yard because of the danger of grass and leaves and rocks and twigs. So their ability *to*

> sort of become involved in things is absolutely one hundred percent dependent on the availability of staff to take them. So that whole ability to choose and be independent is gone."

Many community staff commented on the importance of adequate staffing for facilitating activity engagement and community integration:

> Staff 1: "It would be good to have more staffing when we're out on outings. Like we're limited because of behaviours. More staffing and more funding to provide safer environments, that would be good."
>
> Staff 2: "If we don't have enough staffing he wouldn't be able to go out in the community for picnics, for eating in a restaurant, or nothing like that."

In once instance, a community staff reported that he has the decision-making power to increase the staff-to-client ratio if necessary:

> "Fortunately for me, we have great staffing and if I ever needed staffing, I can get extra staffing. That's not a problem. I mean obviously it would be temporary because of our budget."

An additional consequence of inadequate staff support was the use of more intrusive measures, such as the use of mechanical restraints to manage pica. All the staff from HRC agreed that increased staffing, such as the provision of one-on-one support for individuals with severe pica would be helpful:

> "If we could increase our staffing then we could definitely decrease or eliminate restraint types."

9.8.3 Passive Behaviour

The evidence from the two focus groups also revealed two other reasons why more intensive staffing is required for managing pica. First, pica was reported to be a passive behaviour and consequently more difficult to notice, particularly if staff are supporting other individuals with high needs.

> Staff 1: “Pica can be a more passive behaviour, something else is going to take precedence over it, like an aggression or a severe self-injury. Pica is always going to be an issue.”
>
> Staff 2: “You’re right. A good example of someone, we had pica behaviour, actually you guys had him after we did. But it is passive and sometimes it’s hidden because we came in one morning on the scene and thought why does the seat on the exercise bike look so unusual? Because over a period of a few days, very quietly reached underneath and pulled all the stuffing out of the seat. But so from first glance it looked fine until there was, only thing left was the fabric and springs. So it’s one of those things that we have to be so aware of because you know, it’s not like someone who is disturbed behaviour and is aggressive or throws something, you see it happen. These people can be so, it’s so passive. They can do it over a period of a full day.”
>
> Staff 3: “Same type of incident. I believe we’re probably talking about the same fellow but he will hide his pica materials in different spots and you may not find them but another pica resident will find them and it becomes quite challenging.”
>
> Staff 2: “To find all the hiding spots.”
>
> Staff 3: “That’s right.”

This dialogue illustrates that persons with pica need close supervision because of the often hidden nature of the behaviour, as persons with pica may hide pica items in secret spots or in pockets for later consumption.

9.8.4 Other Challenging Behaviours

Persons with pica also need increased supervision because they often exhibit more than one challenging behaviour. The majority of staff reported that the person(s) they support have other concurrent challenging behaviours that are difficult to manage. Staff from the facility and the community, for example, indicated that individuals with pica tend to exhibit destructive behaviours (tearing or ripping of paper, fabrics, furniture, or personal belongings) and wandering to gain access to items to ingest. Community staff also reported a range of other behaviours that the persons with pica exhibited, including grabbing others, darting/running away, hair-pulling (trichotillomania), intimidation of others, and the regurgitation of previously swallowed food.

9.9 Functioning Level of the Individual

A major barrier identified by many participants in the management of pica was that the person(s) they supported with pica were very low functioning. Consequently, the prevalent feeling was that it was difficult to change their behaviour because the individuals did not understand the dangers of pica and were unable to follow instructions or learn more adaptive behaviours. Below, I examine some of the issues that suggest that the functioning level of the person can be a significant barrier to understanding and reducing their pica behaviour. The level-of-functioning data is analyzed into three categories: cognitive and communication limitations, lack of interest, and hidden symptoms.

9.9.1 Cognition and Communication

Most of the staff perceived that the individuals that they support do not have the capacity to learn from new interventions. This is illustrated in the following responses:

> “She doesn’t have any verbal communication skills. So, I do tell her that’s dangerous or I do try and tell her the reasons why but I’m not really sure if she even understands that much.”
>
> “The individuals we support are very low functioning. You cannot have instruction with them because they remember probably for an hour. And then later it’s forgotten.”

This perception hindered community staff from seeking out help from other professionals or trying other interventions.

9.9.2 Lack of interest

Half of the community and facility staff expressed frustration that the individuals they support have very limited interests which makes it difficult to engage them in alternative activities. The following excerpt illustrates this point:

> "My lady is very uninterested in anything, much like yours. Nothing interests her other than maybe if you ask her if she wants a piece of gum…She's non-verbal. She signs yes or no, where she uses please for yes. There's just, other than swimming, there's nothing that you can see that she enjoys…But there's nothing that motivates her. We get no sign from her that there's something that she really enjoys that you could use that. So that makes it really hard and frustrating because you want to be able to find that thing but it just, you know, it isn't there."

A staff from the facility echoed a similar concern:

> "The one thing about pica is that it's generally tied in with developmental level and functional level so if they do function at that lower level of intellectual disability, it limits the different things you can do for them functionally. So that's one thing that works against keeping them busy."

Staff also have difficulty in finding toys and activities that are both stimulating to the individual and not easily destroyed:

> "In terms of things to keep him occupied, I've tried buying him balls and zippers and things like that but they get thrown underneath his bed and then eventually they get picked apart and eaten."

Thus, staff suggested that one needs to be creative in finding activities that are safe and enjoyable for the individuals with pica.

9.9.3 Hidden Symptoms

Another issue related to lower-functioning individuals is that it is difficult for staff to know whether persons are experiencing medical symptoms from the ingestion of inedibles. The majority of staff reported that persons with pica are non-verbal and therefore do not have the ability to articulate how they are feeling and if they have ingested something. There was a pervasive belief among staff from both settings that one could never be certain if the person had ingested something. Many of the community staff expressed that it is guessing game with regard to the individual's health. One staff remarked:

> "But how do you know? Like we didn't know in our house that the hairball was forming until she was very, very ill. So how do you know they're not getting obstructed bowels?"

Another staff offered their solution:

> "We've actually, I don't know about you guys but we have a standing order for an ultrasound now. So that every few months we get it."

To sum up, the focus groups revealed that many staff felt frustrated in supporting individuals with pica because of their lower functioning level. Communication impairments made it difficult to understand the behaviour and to monitor its associated medical symptoms, while limited or non-existent interest in alternate forms of stimulation seemed to be an outcome of severe/profound cognitive impairment and made it difficult to find ways to keep individuals occupied. Unfortunately, more than half of the staff in both settings perceived that, apart from environmental controls, there were few alternatives for managing pica because of the person's functioning level.

9.10 Conclusions

These conclusions represented the findings from the qualitative component of a larger study that combined both qualitative and quantitative methods. The findings from the focus groups revealed a number of related themes that highlighted the barriers to managing pica and also the facilitators that help staff reduce the likelihood of pica on a day-to-day basis.

Some of the main factors that staff identified as being helpful in the management of pica were:

- Prevention
- Knowing the individual
- Support Network

Prevention, in the form of environmental controls and staff monitoring, is the most common strategy used to reduce the risk of pica. Providing alternative stimulation in the form of toys or engagement in activities that the individual prefers is also a contributing factor to the prevention of pica. In other words, when individuals are occupied they are less likely to have the time and the opportunity to seek out inedibles. In addition, knowing the individual in terms of the items they prefer and the severity of their pica helps staff in trying and developing strategies that are specific and appropriate to each individual. A strong support network was also identified as a key factor to accessing information and professional support, as well for providing consistency in the management of pica.

There are also a number of specific challenges that staff reported in the management of pica. The staff often spoke of frustration and feelings that they were not doing their job due to the following issues/themes:

- Inadequate staff support
- Lower Functioning Level of the Individual
- Lack of Knowledge

Inadequate staff support is a concern in both settings. In the facility, inadequate staff support leads to the use of more intrusive interventions for dealing with pica, while fewer social and recreational outings for individuals is a consequence of inadequate staffing levels in both settings. The lack of understanding regarding the function/cause of pica and a lack of understanding of the service system also hinder staff from accessing information and trying new approaches. Family and the community also do not have an adequate understanding of the behavior and how to manage it. This leads to frustration for staff when dealing with family, and feelings of embarrassment for staff and individuals with pica while in the community. The lower functioning level of the persons with pica is another obstacle for staff because of difficulty in finding activities and interests in non-verbal persons, as well as trying new strategies and ideas for managing pica. It also makes monitoring individuals' health status more challenging.

Some of these barriers are more prominent depending on the setting. The barriers specific to the community are a fragile network of support and lack of knowledge. Many staff in the community spoke of poor relations between full-time and part-time staff, and the fact that part-time staff are not committed to following protocols. This leads to a lack of cohesion with respect to a consistent approach to managing pica. Half of the community staff also have difficulty accessing or receiving good medical support due to physicians' lack of knowledge or interest in supporting persons with ID. The majority of community staff do not have access to or knowledge of specialized clinical support services (e.g., behavioural therapists, psychologists, and psychiatrists). Thus, most staff are left to manage pica without any input or suggestions from professionals. Finally, lack of knowledge regarding pica among community staff appears to be perpetuated by the closed and insular developmental service system. Staff reported that if there was better interagency communication across the service system then agencies could share useful information with staff in the form of case examples and interventions.

The primary barrier noted by participants at HRC is inadequate staff support. They have relatively small staff-to-client ratios even though they are supporting persons with severe and profound ID and complex behavioural needs. Staff said that they needed more support as two staff members for every eight residents was not always sufficient, particularly for persons with severe pica behaviour and for engagement in activities and outings. Consequently mechanical restraints are used and individuals are excluded from activities due to safety concerns. Further, most staff consider the large number of persons with pica at HRC to be a barrier in managing the behaviour as staff are forced to use “block” or group strategies to manage pica rather than individualized strategies. A few staff even considered the grouping issue to be a barrier, pointing out that individuals with pica are more difficult to supervise when together. This is due to the fact that pica behaviour impacts on other residents with pica (destruction of personal belongings puts other residents with pica at risk), and that they live in more barren environments in which all potential pica items are removed rather than selected items that are specific to an individual. A more detailed discussion of these themes and their meanings for policy and practice will be discussed in section 11.0.

10.0 Limitations of the Study

There were a number of limitations to the present study. To begin with, only ten staff participated in this study (four from the facility and six from community agencies). A larger sample would have enabled the researcher to develop the themes further. Another limitation is that the findings of the present study are not generalizable beyond the staff that participated in the focus groups. However, the results of the study have led to the development of themes and sub-themes which may be applicable to other facility and community staff with different or similar experiences supporting persons with ID and pica.

11.0 Implications for Practice

The themes that emerged from this study—prevention, support network, knowing the individual, inadequate staff support, lack of knowledge, and functioning level of the individual are interrelated. This gives us insight into the support needs of persons with pica as well as demonstrating the complexities and barriers which characterize the difficulties in supporting persons with pica. Moreover, the findings contribute to an understanding of the nature of pica behaviour. It is clear from the staff's perspective that overall there is little known about how best to support persons with pica. However, with a new understanding of the facilitators and barriers of managing pica we can now consider what sorts of adjustments the service system might make in order to maximize and improve the potential for enhancing supports of persons with pica. The implications of each theme on the service system will be discussed more fully in this section and specifically in the context of the deinstitutionalization movement in Ontario.

Prevention is the predominant approach to managing pica in both settings indicating that both settings are taking a proactive and minimally intrusive approach. Maintaining a clean and pica-friendly living environment, staff monitoring, and the provision of alternative stimulation was reported to be useful. Prevention, however, has its costs. The living environment likely needs to be modified, particularly for those with severe pica. With the movement toward integrating the remaining individuals with ID and pica into the community by 2009, the question of what is an appropriate "home" environment for persons with pica in the community has been raised. Considerations should include whether to design homes specifically for persons with pica, thus congregating persons with similar disabilities/behaviours together, or whether persons with pica should live with other individuals with less challenging behaviours. Based on the opinions of staff at HRC, persons with pica should live in smaller personalized living environments together with individuals without pica even though the other residents may need to secure their personal belongings and keep them out of reach. That way, individuals with pica can reside in a more home-like environment where only items that the person prefers to ingest are eliminated or protected in the home, making them easier to support. Developing and providing appropriate community homes for persons with pica will involve community planning at all levels: MCSS, agency planning, and individual planning. It is hoped that direct-care staff from the facilities will be able to voice their concerns or suggestions on the physical design of homes and the grouping of individuals with pica with other residents in the community.

In addition, individuals with pica also require close supervision to ensure their safety. A key barrier to supporting individuals with pica effectively is lack of adequate staff support. Without adequate staff supervision, individuals with the behaviour will lead relatively isolated lives because their activity involvement is mostly dependent on the availability of appropriate staffing levels. Thus, increased staffing ratios are needed to allow for greater community integration. Also, lack of adequate staff supervision will likely engender more intrusive methods for dealing with the behaviour, such as mechanical restraints and the use of psychotropic medication. It was also found that individuals with pica show multiple challenging behaviours and hence require intensive supervision. This is consistent with the literature insofar as many individuals with challenging behaviours often present with more than one type of behaviour (Emerson et al., 2001; Sigafoos, Arthur, O'Reilly, 2003). This further supports the notion that persons with pica are difficult to manage because they often have other comorbid behaviours and as such staff need to be skilled and effectively supported if they are to be able to provide quality support. Services and interventions will be fairly complex and difficult to maintain because of the nature of pica and the range of other behaviours that individuals may present, as there could be multiple functions and environmental setting conditions to consider. This study therefore suggests that the MCSS should commit more resources to individuals with high needs, particularly for those with pica, to improve staffing levels.

The staff in both settings also recognized that the management of pica should be individualized. This is consistent with the current thinking on treating behavioural problems (Rush & Allen, 2000). Researchers and practitioners alike need to recognize the individual differences among persons with pica. They should take the time to investigate the function of the behaviour, try different approaches, and consult with people that know the individual best, such as staff and family.

At present there appears to be little interagency communication and collaboration for dealing with high-need individuals in the community. Consequently, information on interventions and strategies to manage pica is not being shared. This further perpetuates the lack of knowledge among community agencies and their staff. Staff in the community often feel alone and isolated in the system, and many suggested that contact with other staff facing similar issues would be helpful. Facility and community agencies have developed considerable experience in dealing with and managing pica and thus interagency collaboration would help bring together the skills and experience of staff from a number of agencies to help each other deal with pica. While barriers still exist in terms of interagency collaboration, the MCSS is making strides in this area by developing networks of specialized support and video-conferencing so that developmental service agencies have access to professionals to help them support individuals with high needs (MCSS, 2006). However, this network will only be effective if all parties involved, (including the executive directors, board of directors, managers, and staff of each developmental service organization) are knowledgeable of this service and how they can go about making a referral. It seems that many agencies “make do” with what they have and wait until the pica behaviour becomes unmanageable before seeking professional supports. This practice likely leads to the persistence of pica across the lifespan for many individuals. This points to the fact that organizations and staff need to be aware of the importance of being knowledgeable about the service system and connected to a network of professional support. The MCSS specialized clinical networks should be responsible for fostering communication, information sharing, and problem solving between agencies regarding the management of pica.

The management of a complex behaviour such as pica requires services and supports from various disciplines. Currently, the facility provides the most comprehensive support network that is available, while access to professional services is variable across community group homes and agencies. As indicated by the staff, health care professionals such as physicians need education about pica, particularly concerning its symptoms and complications. All community staff emphasized the importance that physicians should be specially trained in their curriculum to address the needs of persons with intellectual disabilities and be knowledgeable of their specific health needs. Not infrequently, community staff felt that their physician was fearful of the person they support or that they did not take their concerns seriously. It is essential that physicians are appropriately trained in both the health and behavioural/mental health needs of persons with ID. Access to clinical professionals was the least mentioned support in the community. In contrast, the facility had access to clinical professionals such as behavioural consultants on a daily basis and had monthly visits from a psychiatrist. Access to clinical supports is essential for developing effective intervention plans for managing pica. It is noteworthy that a general trend found in the focus groups was that staff are focusing their efforts on managing the behaviour instead of developing treatment that addresses the function or cause of pica. The literature is quite clear in supporting the functional assessment of challenging behaviour to ensure the development of an effective intervention plan (Rush & Allen, 2000; Sigafoos, Arthur, O'Reilly, 2003). A functional assessment can provide caregivers with a better understanding of the behaviour, resulting in better tailored interventions and environments.

Staff generally felt that there was a lack of information regarding pica and that they had a lack of options for managing the behaviour. This finding implies that staff need better education and training in the management of pica. Education for the family and other key persons about pica and the function and management of behavioural problems is also necessary to support intervention efforts across all settings. Information needs to be provided directly to caregivers, including staff and family through training, meetings, and information sheets. The specialized clinical networks that the MCSS are developing should be responsible for disseminating information related to best practices and effective supports.

The finding that staff are frustrated in finding alternative activities for individuals with pica highlights the need for staff training in finding ways to identify preferences and leisure activities among individuals who are lower functioning and non-verbal. Individuals with severe and profound cognitive impairments often display low activity involvement and are totally dependent on others to engage in activities (Jones, Perry, Lowe, Felce, Toogood, Dunstan, Allen, & Pagler, 1999). Therefore, staff need education and training on how to encourage activity engagement among persons with severe and profound ID. The role of staff should not only be to provide basic care but to keep individuals engaged in social and recreational activities so that pica is less likely to occur. This is a particularly important intervention if pica is found to have a sensory function for the individual.

In conclusion, to the best of our knowledge this is the first study to examine the perspectives of direct-care staff in supporting persons with ID and pica. The themes that emerged from the focus groups raise the level of understanding and awareness about the factors that are helpful in managing pica as well as the barriers. The findings provide validation that persons with ID and pica have distinct support needs and that services in the community need to be enhanced for those with ID, especially in the domain of clinical services. This is very important in the context of the closure of Ontario's three remaining facilities and the influx of persons with pica and other complex needs into the community. The major insight of this study is that a preventative approach is advised by direct-care staff, particularly in the form of environmental control and alternative stimulation. Finally, the findings from staff from both settings suggest that lack of knowledge and information regarding pica must be addressed. Education and training of staff for the management of pica should be a priority and can be enhanced through interagency communication and sharing of ideas among direct staff. Future studies should conduct focus groups with families who have children with ID and pica, so that their perspectives could be understood and taken into consideration to assist with the planning of supports and practice guidelines for persons with pica.

12.0 Synthesis of Findings

This final section draws together the findings from the quantitative and qualitative results of this thesis. Both approaches provide converging evidence that persons with pica are characterized by severe cognitive and communication impairments. Results also suggest that pica is associated with several negative quality-of-life outcomes. The quantitative results indicate that persons with pica have a greater likelihood of not having a strong and supportive relationship with family, and fewer social contacts. Moreover, persons with pica were less likely to participate in social and recreational activities after adjusting for a number of factors. The qualitative results suggested reasons why persons with pica are sometimes restricted from participating in activities such as safety concerns and poor staff to client ratios. Also, focus groups revealed that persons with pica often live in more barren, less personalized living environments. This is particularly true for persons with pica in the facility where there are a larger numbers of individuals to support. Further, comments from community staff support the notion that community integration for persons with pica is limited. Outings seem to be limited to familiar locations, in order to avoid embarrassment or negative reactions from the public, in turn limiting the communities' exposure to pica.

According to the quantitative findings, persons with pica are more likely to receive intensive supervision. Statements by staff members highlight the constant vigilance that is involved in supporting someone with pica in terms of checking the environment and worrying about their safety. Both studies also point to the behavioural complexity of persons with ID and pica. Persons with pica were shown to have multiple challenging behaviours. Staff comments also illustrated that specific behaviours such as wandering and destruction of personal belongings seem to go hand in hand with pica to facilitate the behaviour. Persons with pica destroy personal belongings to allow them to swallow the smaller parts that have been broken off of the original object. With regard to inappropriate sexual behaviour and public disrobing, staff at HRC noted that individuals with pica were opportunistic and would often try and grab an item to ingest during personal hygiene routines (bathing, dressing) when staff are distracted. Often that meant that the individual would try and escape a routine when they were not clothed to find and/or retrieve an inedible object. Staff also provided anecdotal evidence that persons with severe pica are lower functioning, have greater motivation, and possibly are addicted to particular substances (i.e., nicotine from cigarette butts). An interesting extension of this study would be to look at factors that distinguish the severity or frequency of pica.

The predominant approach to managing pica was behaviour management in the facility settings. However, the focus groups further revealed that environmental control was the primary way in which the behaviour was managed. An array of behavioural interventions were also detailed in the focus groups and included redirection, differential reinforcement of an alternative behaviour (keeping an individual involved in activities so that pica is less likely to occur), positive and negative reinforcement in the form of verbal praise or reprimand, response blocking, and mechanical restraints. Mechanical restraints were reported to be used in both community and facility settings for individuals in which pica was considered life-threatening.

Though few medical correlates were found to be associated with pica in the quantitative study, many of the staff members' stories emphasized the medical complications that arise from pica and the fact that the persons they supported needed to endure invasive medical procedures.

Focus groups indicated that staff struggle with supporting persons with pica. Staff members’ statements highlight some of the important barriers (e.g., inadequate staff support, functioning level of the individual, and lack of knowledge) facing caregivers that need to be addressed to provide better supports. A continuum of supports will help address these issues as well as training and education to better understand and manage the behaviour.

To conclude, this work clearly articulates the characteristics and complex needs of this subpopulation. These results suggest that staff need appropriate skills and resources if they are to provide good quality supports in the community, as well attention needs to be paid to families who are also providing support. Appropriate planning of housing, clinical services, and staff training is needed to meet the challenge of supporting adults with ID and pica in the community. Although some may question the relevance of planning for supports that focuses on such a small subpopulation of persons with ID, this evidence clearly articulates why more resources (e.g., increased staffing, clinical supports) need to be directed toward persons with pica. It is hoped that the knowledge gleaned from these studies will help better inform support planning for persons with ID and pica.

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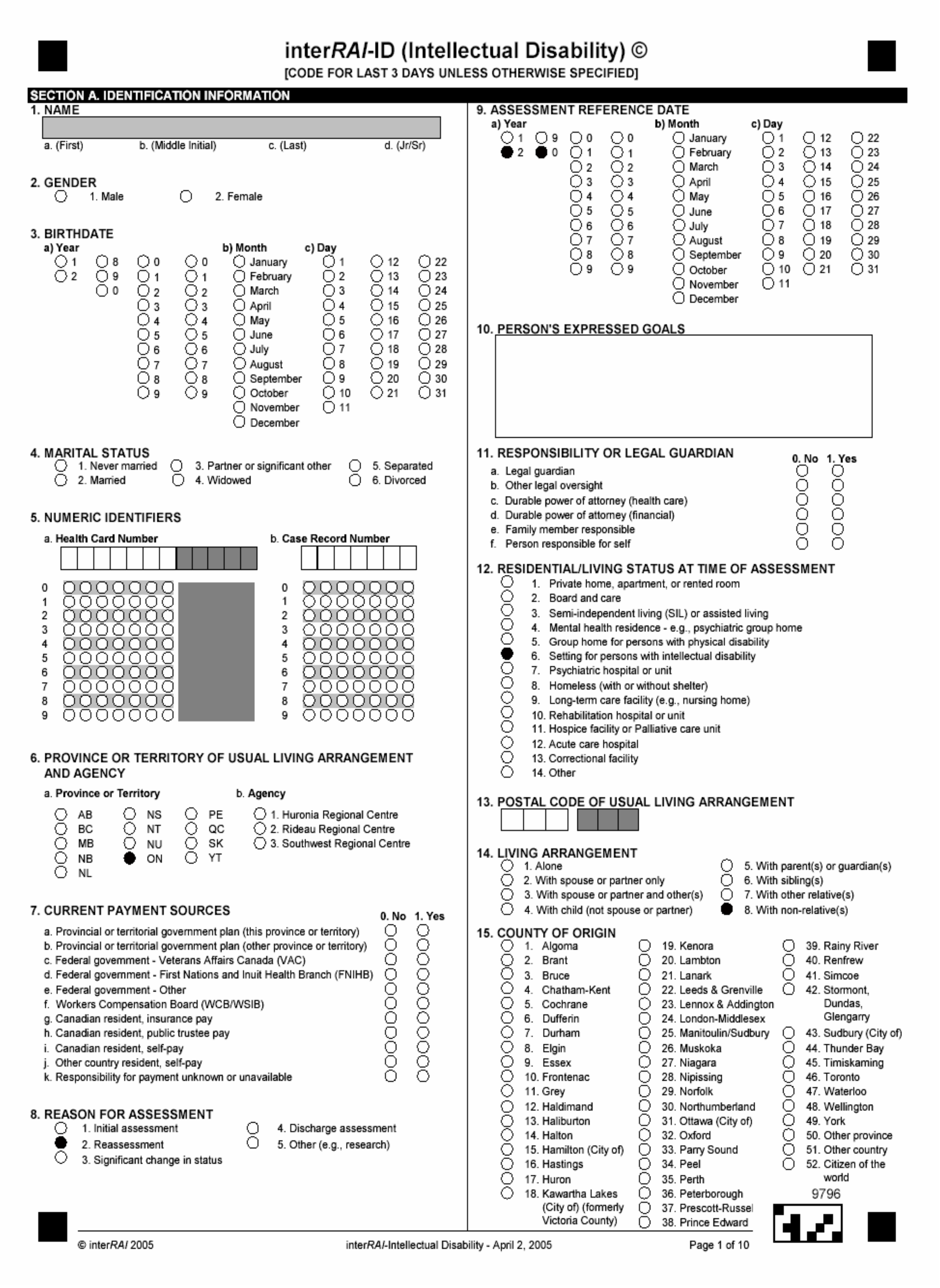
Appendices

Appendix A: interRAI Intellectual Disability version 3.0



interRAI-ID (Intellectual Disability) ©

[CODE FOR LAST 3 DAYS UNLESS OTHERWISE SPECIFIED]

SECTION A. IDENTIFICATION INFORMATION

1. NAME

a. (First) b. (Middle Initial) c. (Last) d. (Jr/Sr)

2. GENDER

○ 1. Male ○ 2. Female

3. BIRTHDATE

a) Year				b) Month	c) Day		
○ 1	○ 8	○ 0	○ 0	○ January	○ 1	○ 12	○ 22
○ 2	○ 9	○ 1	○ 1	○ February	○ 2	○ 13	○ 23
	○ 0	○ 2	○ 2	○ March	○ 3	○ 14	○ 24
		○ 3	○ 3	○ April	○ 4	○ 15	○ 25
		○ 4	○ 4	○ May	○ 5	○ 16	○ 26
		○ 5	○ 5	○ June	○ 6	○ 17	○ 27
		○ 6	○ 6	○ July	○ 7	○ 18	○ 28
		○ 7	○ 7	○ August	○ 8	○ 19	○ 29
		○ 8	○ 8	○ September	○ 9	○ 20	○ 30
		○ 9	○ 9	○ October	○ 10	○ 21	○ 31
				○ November	○ 11		
				○ December			

4. MARITAL STATUS

○ 1. Never married ○ 3. Partner or significant other ○ 5. Separated
○ 2. Married ○ 4. Widowed ○ 6. Divorced

5. NUMERIC IDENTIFIERS

a. **Health Card Number** b. **Case Record Number**

	a. Health Card Number	b. Case Record Number
0	○○○○○○○	○○○○○○○
1	○○○○○○○	○○○○○○○
2	○○○○○○○	○○○○○○○
3	○○○○○○○	○○○○○○○
4	○○○○○○○	○○○○○○○
5	○○○○○○○	○○○○○○○
6	○○○○○○○	○○○○○○○
7	○○○○○○○	○○○○○○○
8	○○○○○○○	○○○○○○○
9	○○○○○○○	○○○○○○○

6. PROVINCE OR TERRITORY OF USUAL LIVING ARRANGEMENT AND AGENCY

a. **Province or Territory**

○ AB	○ NS	○ PE
○ BC	○ NT	○ QC
○ MB	○ NU	○ SK
○ NB	● ON	○ YT
○ NL		

b. **Agency**

○ 1. Huronia Regional Centre
○ 2. Rideau Regional Centre
○ 3. Southwest Regional Centre

7. CURRENT PAYMENT SOURCES

	0. No	1. Yes
a. Provincial or territorial government plan (this province or territory)	○	○
b. Provincial or territorial government plan (other province or territory)	○	○
c. Federal government - Veterans Affairs Canada (VAC)	○	○
d. Federal government - First Nations and Inuit Health Branch (FNIHB)	○	○
e. Federal government - Other	○	○
f. Workers Compensation Board (WCB/WSIB)	○	○
g. Canadian resident, insurance pay	○	○
h. Canadian resident, public trustee pay	○	○
i. Canadian resident, self-pay	○	○
j. Other country resident, self-pay	○	○
k. Responsibility for payment unknown or unavailable	○	○

8. REASON FOR ASSESSMENT

○ 1. Initial assessment
● 2. Reassessment
○ 3. Significant change in status
○ 4. Discharge assessment
○ 5. Other (e.g., research)

9. ASSESSMENT REFERENCE DATE

a) Year				b) Month	c) Day		
○ 1	○ 9	○ 0	○ 0	○ January	○ 1	○ 12	○ 22
● 2	● 0	○ 1	○ 1	○ February	○ 2	○ 13	○ 23
		○ 2	○ 2	○ March	○ 3	○ 14	○ 24
		○ 3	○ 3	○ April	○ 4	○ 15	○ 25
		○ 4	○ 4	○ May	○ 5	○ 16	○ 26
		○ 5	○ 5	○ June	○ 6	○ 17	○ 27
		○ 6	○ 6	○ July	○ 7	○ 18	○ 28
		○ 7	○ 7	○ August	○ 8	○ 19	○ 29
		○ 8	○ 8	○ September	○ 9	○ 20	○ 30
		○ 9	○ 9	○ October	○ 10	○ 21	○ 31
				○ November	○ 11		
				○ December			

10. PERSON'S EXPRESSED GOALS

11. RESPONSIBILITY OR LEGAL GUARDIAN

	0. No	1. Yes
a. Legal guardian	○	○
b. Other legal oversight	○	○
c. Durable power of attorney (health care)	○	○
d. Durable power of attorney (financial)	○	○
e. Family member responsible	○	○
f. Person responsible for self	○	○

12. RESIDENTIAL/LIVING STATUS AT TIME OF ASSESSMENT

○ 1. Private home, apartment, or rented room
○ 2. Board and care
○ 3. Semi-independent living (SIL) or assisted living
○ 4. Mental health residence - e.g., psychiatric group home
○ 5. Group home for persons with physical disability
● 6. Setting for persons with intellectual disability
○ 7. Psychiatric hospital or unit
○ 8. Homeless (with or without shelter)
○ 9. Long-term care facility (e.g., nursing home)
○ 10. Rehabilitation hospital or unit
○ 11. Hospice facility or Palliative care unit
○ 12. Acute care hospital
○ 13. Correctional facility
○ 14. Other

13. POSTAL CODE OF USUAL LIVING ARRANGEMENT

14. LIVING ARRANGEMENT

○ 1. Alone
○ 2. With spouse or partner only
○ 3. With spouse or partner and other(s)
○ 4. With child (not spouse or partner)
○ 5. With parent(s) or guardian(s)
○ 6. With sibling(s)
○ 7. With other relative(s)
● 8. With non-relative(s)

15. COUNTY OF ORIGIN

○ 1. Algoma
○ 2. Brant
○ 3. Bruce
○ 4. Chatham-Kent
○ 5. Cochrane
○ 6. Dufferin
○ 7. Durham
○ 8. Elgin
○ 9. Essex
○ 10. Frontenac
○ 11. Grey
○ 12. Haldimand
○ 13. Haliburton
○ 14. Halton
○ 15. Hamilton (City of)
○ 16. Hastings
○ 17. Huron
○ 18. Kawartha Lakes (City of) (formerly Victoria County)
○ 19. Kenora
○ 20. Lambton
○ 21. Lanark
○ 22. Leeds & Grenville
○ 23. Lennox & Addington
○ 24. London-Middlesex
○ 25. Manitoulin/Sudbury
○ 26. Muskoka
○ 27. Niagara
○ 28. Nipissing
○ 29. Norfolk
○ 30. Northumberland
○ 31. Ottawa (City of)
○ 32. Oxford
○ 33. Parry Sound
○ 34. Peel
○ 35. Perth
○ 36. Peterborough
○ 37. Prescott-Russel
○ 38. Prince Edward
○ 39. Rainy River
○ 40. Renfrew
○ 41. Simcoe
○ 42. Stormont, Dundas, Glengarry
○ 43. Sudbury (City of)
○ 44. Thunder Bay
○ 45. Timiskaming
○ 46. Toronto
○ 47. Waterloo
○ 48. Wellington
○ 49. York
○ 50. Other province
○ 51. Other country
○ 52. Citizen of the world

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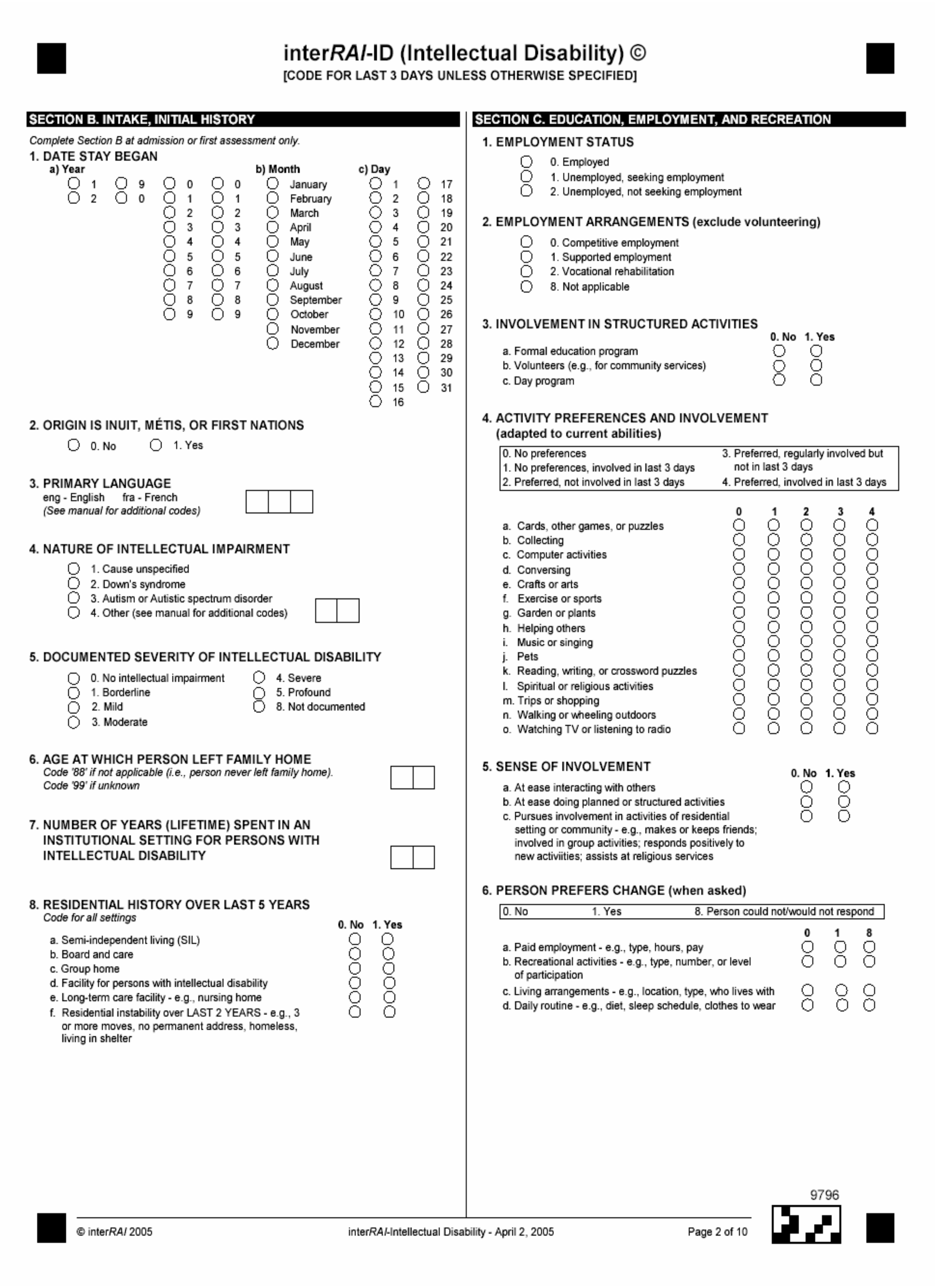

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[CODE FOR LAST 3 DAYS UNLESS OTHERWISE SPECIFIED]

SECTION B. INTAKE, INITIAL HISTORY

Complete Section B at admission or first assessment only.

1. DATE STAY BEGAN

a) Year

○ 1	○ 9	○ 0	○ 0
○ 2	○ 0	○ 1	○ 1
		○ 2	○ 2
		○ 3	○ 3
		○ 4	○ 4
		○ 5	○ 5
		○ 6	○ 6
		○ 7	○ 7
		○ 8	○ 8
		○ 9	○ 9

b) Month

○ January
○ February
○ March
○ April
○ May
○ June
○ July
○ August
○ September
○ October
○ November
○ December

c) Day

○ 1	○ 17
○ 2	○ 18
○ 3	○ 19
○ 4	○ 20
○ 5	○ 21
○ 6	○ 22
○ 7	○ 23
○ 8	○ 24
○ 9	○ 25
○ 10	○ 26
○ 11	○ 27
○ 12	○ 28
○ 13	○ 29
○ 14	○ 30
○ 15	○ 31
○ 16	

2. ORIGIN IS INUIT, MÉTIS, OR FIRST NATIONS

○ 0. No ○ 1. Yes

3. PRIMARY LANGUAGE

eng - English fra - French ☐☐☐
(See manual for additional codes)

4. NATURE OF INTELLECTUAL IMPAIRMENT

○ 1. Cause unspecified
○ 2. Down's syndrome
○ 3. Autism or Autistic spectrum disorder
○ 4. Other (see manual for additional codes) ☐☐

5. DOCUMENTED SEVERITY OF INTELLECTUAL DISABILITY

○ 0. No intellectual impairment
○ 1. Borderline
○ 2. Mild
○ 3. Moderate
○ 4. Severe
○ 5. Profound
○ 8. Not documented

6. AGE AT WHICH PERSON LEFT FAMILY HOME

Code '88' if not applicable (i.e., person never left family home).
Code '99' if unknown ☐☐

7. NUMBER OF YEARS (LIFETIME) SPENT IN AN INSTITUTIONAL SETTING FOR PERSONS WITH INTELLECTUAL DISABILITY

☐☐

8. RESIDENTIAL HISTORY OVER LAST 5 YEARS

Code for all settings

	0. No	1. Yes
a. Semi-independent living (SIL)	○	○
b. Board and care	○	○
c. Group home	○	○
d. Facility for persons with intellectual disability	○	○
e. Long-term care facility - e.g., nursing home	○	○
f. Residential instability over LAST 2 YEARS - e.g., 3 or more moves, no permanent address, homeless, living in shelter	○	○

SECTION C. EDUCATION, EMPLOYMENT, AND RECREATION

1. EMPLOYMENT STATUS

○ 0. Employed
○ 1. Unemployed, seeking employment
○ 2. Unemployed, not seeking employment

2. EMPLOYMENT ARRANGEMENTS (exclude volunteering)

○ 0. Competitive employment
○ 1. Supported employment
○ 2. Vocational rehabilitation
○ 8. Not applicable

3. INVOLVEMENT IN STRUCTURED ACTIVITIES

	0. No	1. Yes
a. Formal education program	○	○
b. Volunteers (e.g., for community services)	○	○
c. Day program	○	○

4. ACTIVITY PREFERENCES AND INVOLVEMENT (adapted to current abilities)

0. No preferences	3. Preferred, regularly involved but not in last 3 days
1. No preferences, involved in last 3 days	4. Preferred, involved in last 3 days
2. Preferred, not involved in last 3 days	

	0	1	2	3	4
a. Cards, other games, or puzzles	○	○	○	○	○
b. Collecting	○	○	○	○	○
c. Computer activities	○	○	○	○	○
d. Conversing	○	○	○	○	○
e. Crafts or arts	○	○	○	○	○
f. Exercise or sports	○	○	○	○	○
g. Garden or plants	○	○	○	○	○
h. Helping others	○	○	○	○	○
i. Music or singing	○	○	○	○	○
j. Pets	○	○	○	○	○
k. Reading, writing, or crossword puzzles	○	○	○	○	○
l. Spiritual or religious activities	○	○	○	○	○
m. Trips or shopping	○	○	○	○	○
n. Walking or wheeling outdoors	○	○	○	○	○
o. Watching TV or listening to radio	○	○	○	○	○

5. SENSE OF INVOLVEMENT

	0. No	1. Yes
a. At ease interacting with others	○	○
b. At ease doing planned or structured activities	○	○
c. Pursues involvement in activities of residential setting or community - e.g., makes or keeps friends; involved in group activities; responds positively to new activiities; assists at religious services	○	○

6. PERSON PREFERS CHANGE (when asked)

0. No 1. Yes 8. Person could not/would not respond

	0	1	8
a. Paid employment - e.g., type, hours, pay	○	○	○
b. Recreational activities - e.g., type, number, or level of participation	○	○	○
c. Living arrangements - e.g., location, type, who lives with	○	○	○
d. Daily routine - e.g., diet, sleep schedule, clothes to wear	○	○	○

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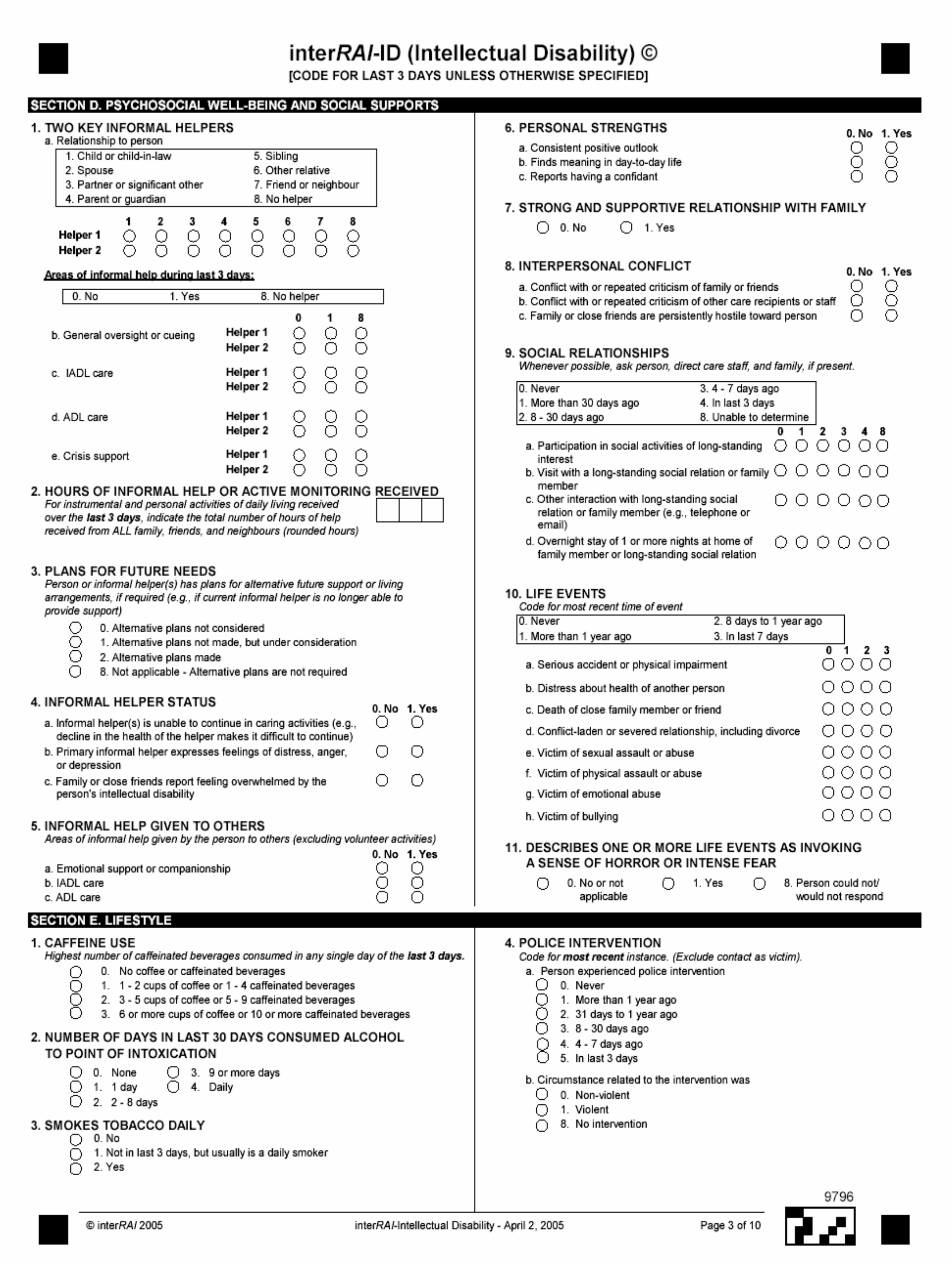

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[CODE FOR LAST 3 DAYS UNLESS OTHERWISE SPECIFIED]

SECTION D. PSYCHOSOCIAL WELL-BEING AND SOCIAL SUPPORTS

1. TWO KEY INFORMAL HELPERS

a. Relationship to person

1. Child or child-in-law	5. Sibling
2. Spouse	6. Other relative
3. Partner or significant other	7. Friend or neighbour
4. Parent or guardian	8. No helper

	1	2	3	4	5	6	7	8
Helper 1	○	○	○	○	○	○	○	○
Helper 2	○	○	○	○	○	○	○	○

Areas of informal help during last 3 days:

0. No 1. Yes 8. No helper

		0	1	8
b. General oversight or cueing	**Helper 1**	○	○	○
	Helper 2	○	○	○
c. IADL care	**Helper 1**	○	○	○
	Helper 2	○	○	○
d. ADL care	**Helper 1**	○	○	○
	Helper 2	○	○	○
e. Crisis support	**Helper 1**	○	○	○
	Helper 2	○	○	○

2. HOURS OF INFORMAL HELP OR ACTIVE MONITORING RECEIVED

*For instrumental and personal activities of daily living received over the **last 3 days**, indicate the total number of hours of help received from ALL family, friends, and neighbours (rounded hours)* ☐☐☐

3. PLANS FOR FUTURE NEEDS

Person or informal helper(s) has plans for alternative future support or living arrangements, if required (e.g., if current informal helper is no longer able to provide support)

- ○ 0. Alternative plans not considered
- ○ 1. Alternative plans not made, but under consideration
- ○ 2. Alternative plans made
- ○ 8. Not applicable - Alternative plans are not required

4. INFORMAL HELPER STATUS

	0. No	1. Yes
a. Informal helper(s) is unable to continue in caring activities (e.g., decline in the health of the helper makes it difficult to continue)	○	○
b. Primary informal helper expresses feelings of distress, anger, or depression	○	○
c. Family or close friends report feeling overwhelmed by the person's intellectual disability	○	○

5. INFORMAL HELP GIVEN TO OTHERS

Areas of informal help given by the person to others (excluding volunteer activities)

	0. No	1. Yes
a. Emotional support or companionship	○	○
b. IADL care	○	○
c. ADL care	○	○

6. PERSONAL STRENGTHS

	0. No	1. Yes
a. Consistent positive outlook	○	○
b. Finds meaning in day-to-day life	○	○
c. Reports having a confidant	○	○

7. STRONG AND SUPPORTIVE RELATIONSHIP WITH FAMILY

○ 0. No ○ 1. Yes

8. INTERPERSONAL CONFLICT

	0. No	1. Yes
a. Conflict with or repeated criticism of family or friends	○	○
b. Conflict with or repeated criticism of other care recipients or staff	○	○
c. Family or close friends are persistently hostile toward person	○	○

9. SOCIAL RELATIONSHIPS

Whenever possible, ask person, direct care staff, and family, if present.

0. Never	3. 4 - 7 days ago
1. More than 30 days ago	4. In last 3 days
2. 8 - 30 days ago	8. Unable to determine

	0	1	2	3	4	8
a. Participation in social activities of long-standing interest	○	○	○	○	○	○
b. Visit with a long-standing social relation or family member	○	○	○	○	○	○
c. Other interaction with long-standing social relation or family member (e.g., telephone or email)	○	○	○	○	○	○
d. Overnight stay of 1 or more nights at home of family member or long-standing social relation	○	○	○	○	○	○

10. LIFE EVENTS

Code for most recent time of event

0. Never	2. 8 days to 1 year ago
1. More than 1 year ago	3. In last 7 days

	0	1	2	3
a. Serious accident or physical impairment	○	○	○	○
b. Distress about health of another person	○	○	○	○
c. Death of close family member or friend	○	○	○	○
d. Conflict-laden or severed relationship, including divorce	○	○	○	○
e. Victim of sexual assault or abuse	○	○	○	○
f. Victim of physical assault or abuse	○	○	○	○
g. Victim of emotional abuse	○	○	○	○
h. Victim of bullying	○	○	○	○

11. DESCRIBES ONE OR MORE LIFE EVENTS AS INVOKING A SENSE OF HORROR OR INTENSE FEAR

○ 0. No or not applicable ○ 1. Yes ○ 8. Person could not/ would not respond

SECTION E. LIFESTYLE

1. CAFFEINE USE

*Highest number of caffeinated beverages consumed in any single day of the **last 3 days**.*

- ○ 0. No coffee or caffeinated beverages
- ○ 1. 1 - 2 cups of coffee or 1 - 4 caffeinated beverages
- ○ 2. 3 - 5 cups of coffee or 5 - 9 caffeinated beverages
- ○ 3. 6 or more cups of coffee or 10 or more caffeinated beverages

2. NUMBER OF DAYS IN LAST 30 DAYS CONSUMED ALCOHOL TO POINT OF INTOXICATION

- ○ 0. None
- ○ 1. 1 day
- ○ 2. 2 - 8 days
- ○ 3. 9 or more days
- ○ 4. Daily

3. SMOKES TOBACCO DAILY

- ○ 0. No
- ○ 1. Not in last 3 days, but usually is a daily smoker
- ○ 2. Yes

4. POLICE INTERVENTION

*Code for **most recent** instance. (Exclude contact as victim).*

a. Person experienced police intervention

- ○ 0. Never
- ○ 1. More than 1 year ago
- ○ 2. 31 days to 1 year ago
- ○ 3. 8 - 30 days ago
- ○ 4. 4 - 7 days ago
- ○ 5. In last 3 days

b. Circumstance related to the intervention was

- ○ 0. Non-violent
- ○ 1. Violent
- ○ 8. No intervention

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[CODE FOR LAST 3 DAYS UNLESS OTHERWISE SPECIFIED]

SECTION F. ENVIRONMENTAL ASSESSMENT

1. HOME ENVIRONMENT

Code for any of the following that make home environment hazardous or uninhabitable. (If temporarily in institution, base assessment on home visit).

0. No 1. Yes 8. Unknown, home not visited or no information

	0	1	8
a. **Disrepair of the home** - e.g., hazardous clutter; inadequate or no lighting in living room, sleeping room, kitchen, toilet, corridors; holes in floor; leaking pipes	○	○	○
b. **Squalid condition** - e.g., extremely dirty, infestation by rats or bugs	○	○	○
c. **Inadequate heating or cooling** - e.g., too hot in summer, too cold in winter	○	○	○
d. **Lack of personal safety** - e.g., fear of violence, safety problem in going to mailbox or visiting neighbours, heavy traffic in street	○	○	○
e. **Limited access to home or rooms in home** - e.g., difficulty entering or leaving home, unable to climb stairs, difficulty manoeuvring within rooms, no railings though needed	○	○	○

SECTION G. COMMUNICATION AND VISION

1. COMMUNICATION METHODS

Code for primary type of expressive communication

○ 1. Verbal (i.e., speech)
○ 2. Non-verbal (e.g., gestures, sign language, sounds, writing)

2. MAKING SELF UNDERSTOOD (Expression)

Expressing information content - both verbal and non-verbal

○ 0. ***Understood*** - Expresses ideas without difficulty
○ 1. ***Usually understood*** - Difficulty finding words or finishing thoughts BUT if given time, little or no prompting required
○ 2. ***Often understood*** - Difficulty finding words or finishing thoughts AND prompting usually required
○ 3. ***Sometimes understood*** - Ability is limited to making concrete requests
○ 4. ***Rarely or never understood***

3. ABILITY TO UNDERSTAND OTHERS (Comprehension)

Understanding verbal information content (however able; with hearing appliance, if used)

○ 0. ***Understands*** - Clear comprehension
○ 1. ***Usually understands*** - Misses some part or intent of message BUT comprehends most conversation
○ 2. ***Often understands*** - Misses some part or intent of message BUT with repetition or explanation can often comprehend conversation
○ 3. ***Sometimes understands*** - Responds adequately to simple, direct communication only
○ 4. ***Rarely or never understands***

4. HEARING

a. Hearing appliance used

○ 0. No ○ 1. Yes

b. Ability to hear (with hearing appliance normally used)

○ 0. ***Adequate*** - No difficulty in normal conversation, social interaction, listening to TV
○ 1. ***Minimal difficulty*** - Difficulty in some environments (e.g., when person speaks softly or is more than 2 metres [6 feet] away)
○ 2. ***Moderate difficulty*** - Problem hearing normal conversation, requires quiet setting to hear well
○ 3. ***Severe difficulty*** - Difficulty in all situations (e.g., speaker has to talk loudly or speak very slowly, or person reports that all speech is mumbled)
○ 4. ***No hearing***

5. VISION

a. Visual appliance used

○ 0. No ○ 1. Yes

b. Ability to see in adequate light (with glasses or with other visual appliance normally used)

○ 0. ***Adequate*** - Sees fine detail, including regular print in newspapers or books
○ 1. ***Minimal difficulty*** - Sees large print but not regular print in newspapers or books
○ 2. ***Moderate difficulty*** - Limited vision; not able to see newspaper headlines but can identify objects
○ 3. ***Severe difficulty*** - Object identification in question but eyes appear to follow objects; sees only light, colours, or shapes
○ 4. ***No vision***

SECTION H. COGNITION

1. MEMORY / RECALL ABILITY

Code for recall of what was learned or known

a. **Short-term memory OK** - Seems or appears to recall after 5 minutes

○ 0. Yes, memory OK
○ 1. Memory problem

b. **Procedural memory OK** - Can perform all or almost all steps in a multitask sequence without cues

○ 0. Yes, memory OK
○ 1. Memory problem

c. **Situational memory OK** - BOTH: Recognizes caregivers' names or faces frequently encountered AND knows location of places regularly visited (e.g., bedroom, dining room)

○ 0. Yes, memory OK
○ 1. Memory problem

2. COGNITIVE SKILLS FOR DAILY DECISION-MAKING

Making decisions regarding tasks of daily life, e.g., when to get up or have meals, which clothes to wear or activities to do

○ 0. ***Independent*** - Decisions consistent, reasonable, and safe
○ 1. ***Modified independence*** - Some difficulty in new situations only
○ 2. ***Minimally impaired*** - In specific recurring situations, decisions become poor or unsafe; cues or supervision necessary at those times
○ 3. ***Moderately impaired*** - Decisions consistently poor or unsafe; cues or supervision required at all times
○ 4. ***Severely impaired*** - Never or rarely makes decisions
○ 5. ***No discernible consciousness, coma***

3. NOW MORE IMPAIRED IN DECISION-MAKING THAN 90 DAYS AGO (or since last assessment if less than 90 days ago)

○ 0. No ○ 1. Yes, more impaired today ○ 8. Uncertain

4. PERIODIC DISORDERED THINKING OR AWARENESS

[Note: Accurate assessment requires conversations with staff, family, and others who have direct knowledge of the person's behaviour over this time.]

0. Behaviour not present
1. Behaviour present, consistent with usual functioning
2. Behaviour present, appears different from usual functioning, e.g., new onset or worsening; different from a few weeks ago

	0	1	2
a. **Easily distracted** - e.g., episodes of difficulty paying attention; gets sidetracked	○	○	○
b. **Episodes of disorganized speech** - e.g., speech is nonsensical, irrelevant, or rambling from subject to subject; loses train of thought	○	○	○
c. **Mental function varies over the course of the day** - e.g., sometimes better, sometimes worse	○	○	○

5. ACUTE CHANGE IN MENTAL STATUS FROM PERSON'S USUAL FUNCTIONING - *e.g., restlessness, lethargy, difficult to arouse, altered environmental perception.*

○ 0. No ○ 1. Yes

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[CODE FOR LAST 3 DAYS UNLESS OTHERWISE SPECIFIED]

SECTION I. HEALTH

1. SELF-REPORTED HEALTH

Ask: *"In general, how would you rate your health?"*

○ 0. Excellent
○ 1. Good
○ 2. Fair
○ 3. Poor
○ 8. Person could not/would not respond

2. HEALTH PROBLEM FREQUENCY

Code for presence in last 3 days

0. Not present	3. Exhibited on 2 of last 3 days
1. Present, but not exhibited in last 3 days	4. Exhibited daily in last 3 days
2. Exhibited on 1 of last 3 days	

	0	1	2	3	4
BALANCE					
a. Dizziness	○	○	○	○	○
b. Unsteady gait	○	○	○	○	○
CARDIAC					
c. Chest pain	○	○	○	○	○
GI STATUS					
d. Acid reflux - regurgitation of acid from stomach to throat	○	○	○	○	○
e. Constipation - no bowel movement in 3 days or difficult passage of hard stool	○	○	○	○	○
f. Diarrhea	○	○	○	○	○
g. Dry mouth	○	○	○	○	○
h. Hypersalivation or drooling	○	○	○	○	○
i. Increase or decrease in normal appetite	○	○	○	○	○
j. Nausea	○	○	○	○	○
k. Vomiting	○	○	○	○	○
OTHER					
l. Blurred vision	○	○	○	○	○
m. Daytime drowsiness or sedation	○	○	○	○	○
n. Difficulty urinating, urinating 3 or more times a night or polyuria	○	○	○	○	○
o. Emergent conditions - e.g., itching, fever, rash, bleeding	○	○	○	○	○
p. Headache	○	○	○	○	○
q. Peripheral edema	○	○	○	○	○
r. Seizures	○	○	○	○	○

3. DYSPNEA (shortness of breath)

○ 0. Absence of symptom
○ 1. Absent at rest, but present when performed moderate activities
○ 2. Absent at rest, but present when performed normal day-to-day activities
○ 3. Present at rest

4. FATIGUE

Inability to complete normal daily activities (e.g., ADLs, IADLs)

○ 0. ***None***
○ 1. ***Minimal*** - Diminished energy but completes normal day-to-day activities
○ 2. ***Moderate*** - Due to diminished energy, unable to FINISH normal day-to-day activities
○ 3. ***Severe*** - Due to diminished energy, unable to START SOME normal day-to-day activities
○ 4. ***Unable to commence any normal day-to-day activities*** - Due to diminished energy

5. EXTRAPYRAMIDAL SYMPTOMS DURING LAST 3 DAYS

	0. No	1. Yes
a. **Akathisia** - Subjective feeling of restlessness or need for movement	○	○
b. **Dyskinesia** - e.g., Chewing, puckering movements of mouth; abnormal irregular movements of lips; rocking or writhing of trunk	○	○
c. **Tremor** - Involuntary rhythmic movements of the fingers, limbs, head, mouth, tongue	○	○
d. **Bradykinesia** - Decrease in spontaneous movements, e.g., reduced body movement, or poverty of facial expression, gestures, speech	○	○
e. **Rigidity** - Resistance to flexion and extension of muscles, e.g., continuous or cogwheeling rigidity	○	○
f. **Dystonia** - Muscle hypertonicity, e.g., muscle spasms or stiffness, protruding tongue, upward deviation of the eyes	○	○
g. **Slow shuffling gait** - Reduction in speed and stride length, usually with a decrease in pendular arm movement	○	○

6. SKIN PROBLEMS

	0. No	1. Yes
a. Major skin problems - e.g. lesions, 2nd- or 3rd-degree burns, healing surgical wounds	○	○
b. Other skin conditions or changes in skin condition - e.g., bruises, rashes, itching, mottling, herpes zoster, intertrigo, eczema	○	○

7. FOOT PROBLEMS - *e.g., bunions, hammer toes, overlapping toes, structural problems, infections, ulcers*

○ 0. No foot problems
○ 1. Foot problems; no limitation in walking
○ 2. Foot problems limit walking
○ 3. Foot problems prevent walking
○ 4. Foot problems; does not walk for other reasons

8. FALLS

○ 0. No fall in last 90 days
○ 1. No fall in last 30 days, but fell 31-90 days ago
○ 2. 1 fall in last 30 days
○ 3. 2 or more falls in last 30 days

9. PAIN SYMPTOMS

[Note: Always ask the person about pain frequency, intensity, and control. Observe person and ask others who are in contact with the person.]

a. **Frequency** with which person complains or shows evidence of pain, including grimacing, teeth clenching, moaning, withdrawal when touched, other non-verbal signs suggesting pain

○ 0. No pain
○ 1. Present, but not exhibited in last 3 days
○ 2. Exhibited on 1 - 2 of last 3 days
○ 3. Exhibited daily in last 3 days

b. **Intensity** of highest level of pain present

○ 0. No pain
○ 1. Mild
○ 2. Moderate
○ 3. Severe
○ 4. Times when pain is horrible or excruciating

c. **Consistency** of pain

○ 0. No pain
○ 1. Single episode during last 3 days
○ 2. Intermittent
○ 3. Constant

d. **Pain control** - Adequacy of current therapeutic regimen to control pain (from person's point of view)

○ 0. No issue of pain
○ 1. Pain intensity acceptable to person, no treatment regimen or change in regimen required
○ 2. Controlled adequately by therapeutic regimen
○ 3. Controlled when therapeutic regimen followed, but not always followed as ordered
○ 4. Therapeutic regimen followed, but pain control not adequate
○ 5. No therapeutic regimen being followed for pain; pain not adequately controlled

10. SCHEDULED TOILETING

○ 0. No ○ 1. Yes

11. BLADDER CONTINENCE

○ 0. ***Continent*** - Complete control; DOES NOT USE any type of catheter or other urinary collection device
○ 1. ***Complete control with any catheter or ostomy over last 3 days***
○ 2. ***Infrequently incontinent*** - Not incontinent over last 3 days, but does have incontinent episodes
○ 3. ***Occasionally incontinent*** - Less than daily
○ 4. ***Frequently incontinent*** - Daily, but some control present
○ 5. ***Incontinent*** - No control present
○ 8. ***Did not occur*** - No urine output from bladder in last 3 days

12. BOWEL CONTINENCE

○ 0. ***Continent*** - Complete control; DOES NOT USE any type of ostomy device
○ 1. ***Complete control with ostomy*** - Control with ostomy device over last 3 days
○ 2. ***Infrequently incontinent*** - Not incontinent over last 3 days, but does have incontinent episodes
○ 3. ***Occasionally incontinent*** - Less than daily
○ 4. ***Frequently incontinent*** - Daily, but some control present
○ 5. ***Incontinent*** - No control present
○ 8. ***Did not occur*** - No bowel movement in last 3

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[CODE FOR LAST 3 DAYS UNLESS OTHERWISE SPECIFIED]

13. MOST SEVERE PRESSURE ULCER

○ 0. No pressure ulcer
○ 1. Any area of persistent skin redness
○ 2. Partial loss of skin layers
○ 3. Deep craters in the skin
○ 4. Breaks in skin exposing muscle or bone
○ 5. Not codeable, e.g., necrotic eschar predominant

14. PRESENCE OF SKIN ULCER OTHER THAN PRESSURE ULCER -

e.g., venous ulcer, arterial ulcer, mixed venous-arterial ulcer, diabetic foot ulcer

○ 0. No ○ 1. Yes

SECTION J. FUNCTIONAL STATUS

1. ADL SELF-PERFORMANCE

*Code for performance over full 24-hour periods, considering all occurrences of the activity in **last 3 days**. For **all ADLs**, if less than 3 episodes over the three-day time frame, code based on most dependent episode.*

0. ***Independent*** - No help -OR- Help, set-up, or supervision provided 1 - 2 times
1. ***Set-up help only*** - Article or device provided or placed within reach 3+ times
2. ***Supervision*** - Oversight or cueing 3+ times -OR- Oversight or cueing 1+ time and physical assistance 1 - 2 times
3. ***Limited assistance*** - Guided manoeuvring of limbs 3+ times -OR- Combination of guided manoeuvring and more help 1 - 2 times
4. ***Extensive assistance*** - Weight-bearing support 3+ times by 1 helper where person still performs 50% or more of subtasks
5. ***Maximal assistance*** - Weight-bearing support 3+ times by 2+ helpers -OR- weight-bearing support for more than 50% of subtasks
6. ***Total dependence*** - Full performance by other(s) during entire period
8. ***Activity did not occur during entire period***

	0	1	2	3	4	5	6	8
a. **Bathing** - How takes full-body bath, shower or sponge bath (EXCLUDE washing of back and hair). Includes how transfers in or out of tub or shower AND how each part of body is bathed; arms, upper and lower legs, chest, abdomen, perineal area.	○	○	○	○	○	○	○	○
b. **Personal hygiene** - How manages personal hygiene, including combing hair, brushing teeth, shaving, applying make-up, washing or drying face and hands (EXCLUDE baths and showers)	○	○	○	○	○	○	○	○
c. **Dressing upper body** - How dresses and undresses (street clothes, underwear) above the waist. Includes prostheses, orthotics, fasteners, pullovers, etc.	○	○	○	○	○	○	○	○
d. **Dressing lower body** - How dresses and undresses (street clothes, underwear) from the waist down, includes prostheses, orthotics, belts, pants, skirts, shoes, and fasteners	○	○	○	○	○	○	○	○
e. **Walking** - How walks between locations on same floor indoors	○	○	○	○	○	○	○	○
f. **Transfer toilet** - How moves on and off toilet or commode	○	○	○	○	○	○	○	○
g. **Toilet use** - How uses the toilet room (or commode, bedpan, urinal), cleanses self after toilet use or incontinent episode, changes pad, manages ostomy or catheter, adjusts clothes (EXCLUDE transfer on/off toilet)	○	○	○	○	○	○	○	○
h. **Bed mobility** - How moves to and from lying position, turns side to side, and positions body while in bed	○	○	○	○	○	○	○	○
i. **Eating** - How eats and drinks (regardless of skill). Includes intake of nourishment by other means, e.g., tube feeding, total parenteral nutrition	○	○	○	○	○	○	○	○

2. DISTANCE WHEELED SELF

Farthest distance wheeled self at one time in last 3 days (includes independent use of motorized wheelchair)

○ 0. Wheeled by others
○ 1. Less than 5 metres (15 feet)
○ 2. 5 - 49 metres (15 - 149 feet)
○ 3. 50 - 99 metres (150 - 299 feet)
○ 4. 100+ metres (300+ feet)
○ 8. Did not use wheelchair

3. PHYSICAL IMPROVEMENT POTENTIAL

	0. No	1. Yes
a. Person believes he/she is capable of improved performance in physical function	○	○
b. Care professional believes person is capable of improved performance in physical function	○	○

4. ADL STATUS IS WORSE THAN 90 DAYS AGO (or since last assessment if less than 90 days ago)

○ 0. No ○ 1. Yes, more impaired today ○ 8. Uncertain

5. IADL SELF-PERFORMANCE AND CAPACITY

*Code for performance in routine activities around the home or in the community during **last 3 days**. Code for capacity based on presumed ability to carry out activity as independently as possible. This will require speculation by the assessor.*

0. ***Independent*** - No help, set-up, or supervision
1. ***Set-up help only***
2. ***Supervision*** - Oversight or cueing
3. ***Limited assistance*** - Help on some occasions
4. ***Extensive assistance*** - Help throughout task but performs 50% or more of task on own
5. ***Maximal assistance*** - Help throughout task but performs less than 50% of task on own
6. ***Total dependence*** - Full performance by others during entire period
8. ***Activity did not occur during entire period*** (DO NOT USE THIS CODE IN SCORING CAPACITY)

P - Performance C - Capacity

		0	1	2	3	4	5	6	8
a. **Meal preparation** - How meals are prepared, e.g., planning meals, cooking, assembling ingredients, setting out food and utensils	**P**	○	○	○	○	○	○	○	○
	C	○	○	○	○	○	○	○	
b. **Ordinary housework** - How ordinary work around the house is performed, e.g., doing dishes, dusting, making bed, tidying up, doing laundry	**P**	○	○	○	○	○	○	○	○
	C	○	○	○	○	○	○	○	
c. **Managing finances** - How bills are paid, chequebook is balanced, household expenses are budgeted, credit card account is monitored	**P**	○	○	○	○	○	○	○	○
	C	○	○	○	○	○	○	○	
d. **Managing medications** - How medications are managed, e.g., remembering to take medicines, opening bottles, taking correct drug dosages, giving injections, applying ointments	**P**	○	○	○	○	○	○	○	○
	C	○	○	○	○	○	○	○	
e. **Phone use** - How telephone calls are made or received (with assistive devices such as large numbers on telephone, amplification as needed)	**P**	○	○	○	○	○	○	○	○
	C	○	○	○	○	○	○	○	
f. **Shopping** - How shopping is performed for food and household items, e.g., selecting items, paying money (EXCLUDE TRANSPORTATION)	**P**	○	○	○	○	○	○	○	○
	C	○	○	○	○	○	○	○	
g. **Transportation** - How travels by public transportation (navigating system, paying fare) or driving self (including getting out of house, into and out of vehicles)	**P**	○	○	○	○	○	○	○	○
	C	○	○	○	○	○	○	○	
h. **Work** - How performs job-related activities, including both cognitive (e.g., planning, sequencing of tasks, adherence to schedules) and physical (e.g., strength, coordination, stamina) aspects (EXCLUDE TRANSPORTATION)	**P**	○	○	○	○	○	○	○	○
	C	○	○	○	○	○	○	○	

6. IADL STATUS IS WORSE THAN 90 DAYS AGO (or since last assessment if less than 90 days ago)

○ 0. No ○ 1. Yes, more impaired today ○ 8. Uncertain

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7. TOTAL HOURS OF EXERCISE OR PHYSICAL ACTIVITY IN LAST 3 DAYS - *e.g., walking*

○ 0. None ○ 1. Less than 1 hour ○ 2. 1 - 2 hours ○ 3. 3 - 4 hours ○ 4. More than 4 hours

SECTION K. ORAL OR NUTRITIONAL STATUS

1. HEIGHT AND WEIGHT

Record (a.) height in centimetres and (b.) weight in kilograms. Base weight on most recent measure in ***last 30 days***

a. **HT** (cm)			b. **WT** (kg)		
○ 1	○ 1	○ 1	○ 1	○ 1	○ 1
○ 2	○ 2	○ 2	○ 2	○ 2	○ 2
○ 0	○ 3	○ 3	○ 0	○ 3	○ 3
	○ 4	○ 4		○ 4	○ 4
	○ 5	○ 5		○ 5	○ 5
	○ 6	○ 6		○ 6	○ 6
	○ 7	○ 7		○ 7	○ 7
	○ 8	○ 8		○ 8	○ 8
	○ 9	○ 9		○ 9	○ 9
	○ 0	○ 0		○ 0	○ 0

2. NUTRITIONAL ISSUES

	0. No	1. Yes
a. Weight loss of 5% or more in **last 30 days,** or 10% or more in **last 180 days**	○	○
b. Weight gain of 5% or more in **last 30 days,** or 10% or more in **last 180 days**	○	○
c. Fluid intake less than 1,000 cc per day (less than four 8-oz cups/day)	○	○

3. CHEWING OR SWALLOWING PROBLEM - *e.g., pain while eating*

○ 0. No ○ 1. Yes

4. RUMINATION

Regurgitation and chewing of previously swallowed food

○ 0. No ○ 1. Yes

5. POLYDIPSIA

In **last 3 days**, inappropriate or excessive fluid consumption, e.g., drinks fluids many times during the day, drinks a huge amount at a time, refuses to stop drinking, drinks secretly from unusual sources

○ 0. No ○ 1. Yes

6. MODE OF NUTRITIONAL INTAKE

○ 0. **Normal** - Swallows all types of food
○ 1. **Modified independent** - e.g., liquid is sipped, takes limited solid food, need for modification may be unknown
○ 2. **Requires diet modification to swallow solid foods** - e.g., mechanical diet (puréed, minced, etc.) or only able to ingest specific foods
○ 3. **Requires modification to swallow liquids** - e.g., thickened liquids
○ 4. **Can swallow only puréed solids AND thickened liquids**
○ 5. **Combined oral and parenteral or tube feeding**
○ 6. **Nasogastric tube feeding only**
○ 7. **Abdominal feeding tube** - e.g., PEG tube
○ 8. **Parenteral feeding only** - Includes all types of parenteral feedings, such as total parenteral nutrition (TPN)

7. DENTAL OR ORAL

	0. No	1. Yes
a. Wears a denture (removable prosthesis)	○	○
b. Has broken, fragmented, loose, or otherwise non-intact teeth	○	○
c. Reports mouth or facial pain or discomfort	○	○
d. Presents with gum (soft tissue) inflammation or bleeding adjacent to natural teeth or tooth fragments	○	○

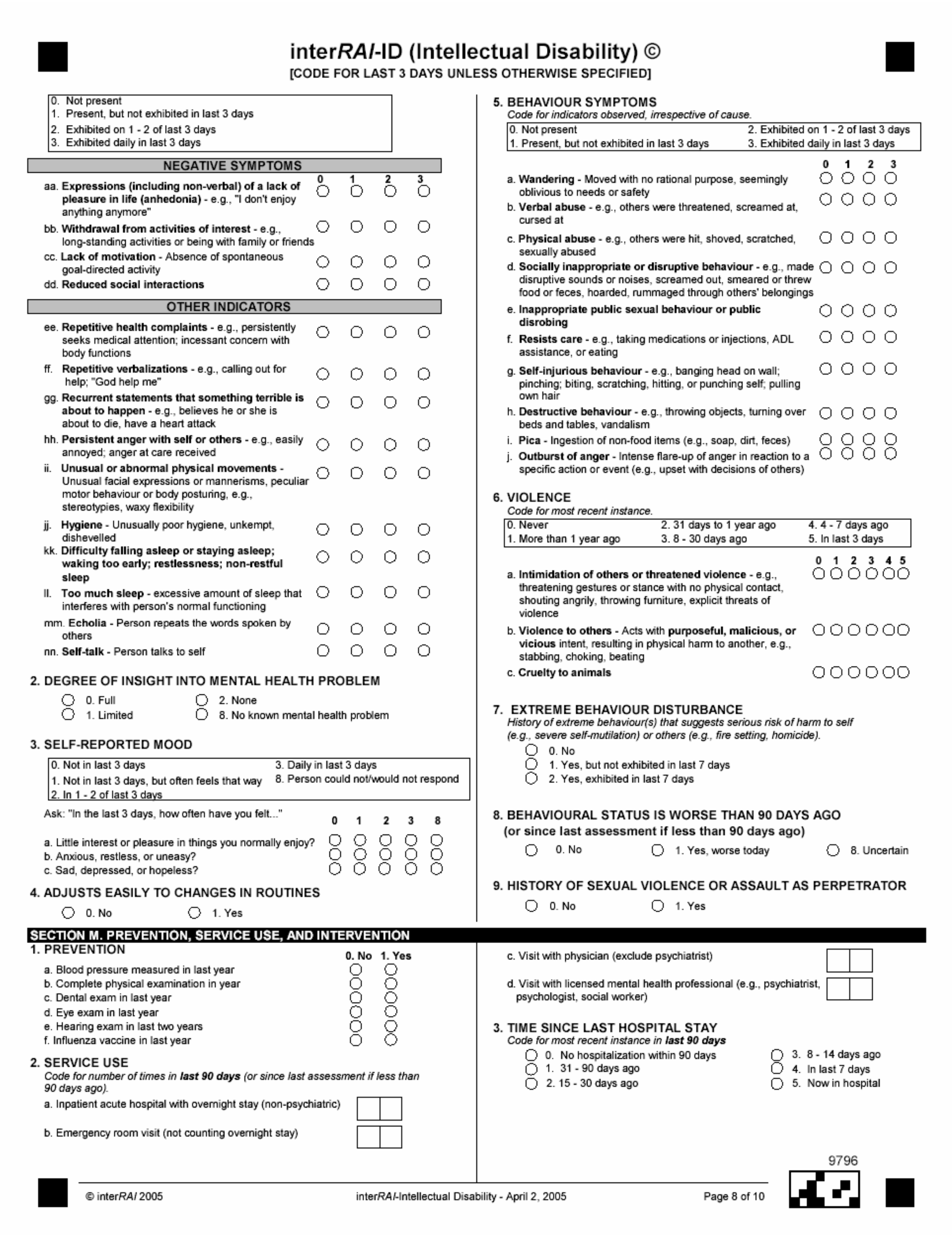
SECTION L. MOOD AND BEHAVIOUR

1. MENTAL STATE INDICATORS

Code for indicators observed, irrespective of assumed cause

0. Not present
1. Present, but not exhibited in last 3 days
2. Exhibited on 1 - 2 of last 3 days
3. Exhibited daily in last 3 days

MOOD DISTURBANCE	0	1	2	3
a. **Cheerful, happy facial expressions** - e.g., smiles or laughs, appears relaxed	○	○	○	○
b. **Sad, pained, or worried facial expressions** - e.g., furrowed brow, constant frowning	○	○	○	○
c. **Crying, tearfulness**	○	○	○	○
d. **Decreased energy** - Statements of decrease in energy level, e.g., "I just don't feel like doing anything"; "I have no energy"	○	○	○	○
e. **Made positive statements** - e.g., "I have a lot to look forward to"; "I am happy"; "I enjoy what I am doing"	○	○	○	○
f. **Made negative statements** - e.g., "Nothing matters"; "Would rather be dead"; "What's the use"; "Regret having lived so long"; "Let me die"	○	○	○	○
g. **Self-deprecation** - e.g., "I am nothing"; "I am of no use to anyone"	○	○	○	○
h. **Expressions of guilt or shame** - e.g., "I've done something awful"; "This is all my fault"; "I am a terrible person"	○	○	○	○
i. **Expressions of hopelessness** - e.g., "There's no hope for the future"; "Nothing's going to change for the better"	○	○	○	○
j. **Inflated self-worth** - e.g., exaggerated self-opinion, arrogance, inflated belief about one's own ability	○	○	○	○
k. **Hyper-arousal** - Motor excitation; unusually high activity; increased reactivity	○	○	○	○
l. **Irritability** - Marked increase in being short-tempered or easily upset	○	○	○	○
m. **Increased sociability or hypersexuality** - Marked increase in social or sexual activity	○	○	○	○
n. **Pressured speech or racing thoughts** - Rapid speech, rapid transition from topic to topic	○	○	○	○
o. **Labile affect** - Affect fluctuates frequently with or without an external explanation	○	○	○	○
p. **Flat or blunted affect** - Indifference, non-responsiveness, hard to get to smile, etc.	○	○	○	○
ANXIETY				
q. **Repetitive anxious complaints or concerns (non-health-related)** - e.g., persistently seeks attention or reassurance regarding schedules, meals, laundry, clothing, relationships	○	○	○	○
r. **Expressions (including non-verbal) of what appear to be unrealistic fears** - e.g., fear of being abandoned, being left alone, being with others; intense fear of specific objects or situations	○	○	○	○
s. **Obsessive thoughts** - Unwanted ideas or thoughts that cannot be eliminated	○	○	○	○
t. **Compulsive behaviour** - e.g., hand washing, repetitive checking of room, counting	○	○	○	○
u. **Intrusive thoughts or flashbacks** - Disturbing memories or images that intrude into thoughts, unexpected recall of adverse events	○	○	○	○
v. **Episodes of panic** - Cascade of symptoms of fear, anxiety, loss of control	○	○	○	○
PSYCHOSIS				
w. **Hallucinations** - False sensory perception, of any type, with or without insight, without corresponding stimuli, e.g., auditory, visual, tactile, olfactory, gustatory hallucinations, excluding command hallucinations	○	○	○	○
x. **Command hallucinations** - Hallucination directing the person to do something or to act in a particular manner, e.g., to harm self or others	○	○	○	○
y. **Delusions** - Fixed false beliefs, e.g., grandiose, paranoid, somatic, excluding beliefs specific to person's culture or religion	○	○	○	○
z. **Abnormal thought process** - e.g., loosening of associations, blocking, flight of ideas, tangentiality, circumstantiality	○	○	○	○



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[CODE FOR LAST 3 DAYS UNLESS OTHERWISE SPECIFIED]

0. Not present
1. Present, but not exhibited in last 3 days
2. Exhibited on 1 - 2 of last 3 days
3. Exhibited daily in last 3 days

NEGATIVE SYMPTOMS	0	1	2	3
aa. **Expressions (including non-verbal) of a lack of pleasure in life (anhedonia)** - e.g., "I don't enjoy anything anymore"	○	○	○	○
bb. **Withdrawal from activities of interest** - e.g., long-standing activities or being with family or friends	○	○	○	○
cc. **Lack of motivation** - Absence of spontaneous goal-directed activity	○	○	○	○
dd. **Reduced social interactions**	○	○	○	○
OTHER INDICATORS				
ee. **Repetitive health complaints** - e.g., persistently seeks medical attention; incessant concern with body functions	○	○	○	○
ff. **Repetitive verbalizations** - e.g., calling out for help; "God help me"	○	○	○	○
gg. **Recurrent statements that something terrible is about to happen** - e.g., believes he or she is about to die, have a heart attack	○	○	○	○
hh. **Persistent anger with self or others** - e.g., easily annoyed; anger at care received	○	○	○	○
ii. **Unusual or abnormal physical movements** - Unusual facial expressions or mannerisms, peculiar motor behaviour or body posturing, e.g., stereotypies, waxy flexibility	○	○	○	○
jj. **Hygiene** - Unusually poor hygiene, unkempt, dishevelled	○	○	○	○
kk. **Difficulty falling asleep or staying asleep; waking too early; restlessness; non-restful sleep**	○	○	○	○
ll. **Too much sleep** - excessive amount of sleep that interferes with person's normal functioning	○	○	○	○
mm. **Echolia** - Person repeats the words spoken by others	○	○	○	○
nn. **Self-talk** - Person talks to self	○	○	○	○

2. DEGREE OF INSIGHT INTO MENTAL HEALTH PROBLEM

○ 0. Full ○ 2. None
○ 1. Limited ○ 8. No known mental health problem

3. SELF-REPORTED MOOD

0. Not in last 3 days
1. Not in last 3 days, but often feels that way
2. In 1 - 2 of last 3 days
3. Daily in last 3 days
8. Person could not/would not respond

Ask: "In the last 3 days, how often have you felt..."	0	1	2	3	8
a. Little interest or pleasure in things you normally enjoy?	○	○	○	○	○
b. Anxious, restless, or uneasy?	○	○	○	○	○
c. Sad, depressed, or hopeless?	○	○	○	○	○

4. ADJUSTS EASILY TO CHANGES IN ROUTINES

○ 0. No ○ 1. Yes

5. BEHAVIOUR SYMPTOMS

Code for indicators observed, irrespective of cause.

0. Not present
1. Present, but not exhibited in last 3 days
2. Exhibited on 1 - 2 of last 3 days
3. Exhibited daily in last 3 days

	0	1	2	3
a. **Wandering** - Moved with no rational purpose, seemingly oblivious to needs or safety	○	○	○	○
b. **Verbal abuse** - e.g., others were threatened, screamed at, cursed at	○	○	○	○
c. **Physical abuse** - e.g., others were hit, shoved, scratched, sexually abused	○	○	○	○
d. **Socially inappropriate or disruptive behaviour** - e.g., made disruptive sounds or noises, screamed out, smeared or threw food or feces, hoarded, rummaged through others' belongings	○	○	○	○
e. **Inappropriate public sexual behaviour or public disrobing**	○	○	○	○
f. **Resists care** - e.g., taking medications or injections, ADL assistance, or eating	○	○	○	○
g. **Self-injurious behaviour** - e.g., banging head on wall; pinching; biting, scratching, hitting, or punching self; pulling own hair	○	○	○	○
h. **Destructive behaviour** - e.g., throwing objects, turning over beds and tables, vandalism	○	○	○	○
i. **Pica** - Ingestion of non-food items (e.g., soap, dirt, feces)	○	○	○	○
j. **Outburst of anger** - Intense flare-up of anger in reaction to a specific action or event (e.g., upset with decisions of others)	○	○	○	○

6. VIOLENCE

Code for most recent instance.

0. Never
1. More than 1 year ago
2. 31 days to 1 year ago
3. 8 - 30 days ago
4. 4 - 7 days ago
5. In last 3 days

	0	1	2	3	4	5
a. **Intimidation of others or threatened violence** - e.g., threatening gestures or stance with no physical contact, shouting angrily, throwing furniture, explicit threats of violence	○	○	○	○	○	○
b. **Violence to others** - Acts with **purposeful, malicious, or vicious** intent, resulting in physical harm to another, e.g., stabbing, choking, beating	○	○	○	○	○	○
c. **Cruelty to animals**	○	○	○	○	○	○

7. EXTREME BEHAVIOUR DISTURBANCE

History of extreme behaviour(s) that suggests serious risk of harm to self (e.g., severe self-mutilation) or others (e.g., fire setting, homicide).

○ 0. No
○ 1. Yes, but not exhibited in last 7 days
○ 2. Yes, exhibited in last 7 days

8. BEHAVIOURAL STATUS IS WORSE THAN 90 DAYS AGO (or since last assessment if less than 90 days ago)

○ 0. No ○ 1. Yes, worse today ○ 8. Uncertain

9. HISTORY OF SEXUAL VIOLENCE OR ASSAULT AS PERPETRATOR

○ 0. No ○ 1. Yes

SECTION M. PREVENTION, SERVICE USE, AND INTERVENTION

1. PREVENTION

	0. No	1. Yes
a. Blood pressure measured in last year	○	○
b. Complete physical examination in year	○	○
c. Dental exam in last year	○	○
d. Eye exam in last year	○	○
e. Hearing exam in last two years	○	○
f. Influenza vaccine in last year	○	○

2. SERVICE USE

*Code for number of times in **last 90 days** (or since last assessment if less than 90 days ago).*

a. Inpatient acute hospital with overnight stay (non-psychiatric) ☐☐

b. Emergency room visit (not counting overnight stay) ☐☐

c. Visit with physician (exclude psychiatrist) ☐☐

d. Visit with licensed mental health professional (e.g., psychiatrist, psychologist, social worker) ☐☐

3. TIME SINCE LAST HOSPITAL STAY

*Code for most recent instance in **last 90 days***

○ 0. No hospitalization within 90 days
○ 1. 31 - 90 days ago
○ 2. 15 - 30 days ago
○ 3. 8 - 14 days ago
○ 4. In last 7 days
○ 5. Now in hospital

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4. MENTAL HEALTH SERVICES

a. **Time since last contact with community mental health agency or professional in last year** - e.g., psychiatrist, social worker.
- ○ 0. No contact in last year
- ○ 1. 31 days or more
- ○ 2. 30 days or less

b. **Number of psychiatric admissions in last 2 years**
○ 0. None ○ 1. 1 - 2 ○ 2. 3 or more

5. FORMAL CARE

*Number of days of contact of at least 15 minutes per day in **last 7 days** or since admission if less than 7 days. Code 0 to 7 days.*

	0	1	2	3	4	5	6	7
a. Developmental Services Worker or direct care staff	○	○	○	○	○	○	○	○
b. Occupational Therapist, Physical Therapst, or Speech Therapist	○	○	○	○	○	○	○	○
c. Recreation Therapist	○	○	○	○	○	○	○	○
d. Nurse	○	○	○	○	○	○	○	○
e. Rehabilitation Worker	○	○	○	○	○	○	○	○

6. FORMAL SERVICES AND TRAINING PROGRAMS

*Code for types of issues that were a major focus of formal services and training programs in **last 30 days** or since admission if less than 30 days ago*

0. No service or program of this type	3. Received 8 to 30 days ago
1. Offered, but refused	4. Received in last 7 days
2. Not received, but scheduled to start within next 30 days	

	0	1	2	3	4
a. **Self-care skills training** - e.g., dressing, eating, hygiene	○	○	○	○	○
b. **Community skills training** - e.g., vocational rehabilitation, transportation, shopping	○	○	○	○	○
c. **Social skills training** - e.g., interpersonal skills, etiquette	○	○	○	○	○
d. **Cognitive skills training** - e.g., help with reading, letters, numbers, colours	○	○	○	○	○
e. **Education on special topics** - e.g, sexuality, safety	○	○	○	○	○
f. **Behaviour management** - e.g., program to reduce unwanted or inappropriate behaviour	○	○	○	○	○
g. **Sensory stimulation programs** - e.g., aromatherapy, Snoezelen room, music therapy	○	○	○	○	○

7. PROJECTED TIME TO DISCHARGE

How long expected to stay in current setting or under the care of this service prior to discharge. Count from assessment reference date, including that day.

- ○ 0. Less than 30 days
- ○ 1. 31 - 90 days
- ○ 2. 91 - 180 days
- ○ 3. 181 days - 1 year
- ○ 4. More than 1 year
- ○ 5. Discharge not expected

SECTION N. DIAGNOSTIC INFORMATION

1. MEDICAL DIAGNOSES

0. Not present	2. Diagnosis present, receiving active treatment
1. Primary diagnosis or diagnoses for current study	3. Diagnosis present, monitored but no active treatment

	0	1	2	3
a. Asthma	○	○	○	○
b. Cerebral Palsy	○	○	○	○
c. Diabetes mellitus	○	○	○	○
d. Hypothyroidism	○	○	○	○
e. Traumatic brain injury	○	○	○	○

Other medical diagnoses

	Diagnosis	Disease Code 0	1	2	3	ICD-10 Code
f.		○	○	○	○	☐☐☐☐.☐☐☐
g.		○	○	○	○	☐☐☐☐.☐☐☐
h.		○	○	○	○	☐☐☐☐.☐☐☐

Add lines as necessary for other disease diagnoses.

2. MENTAL HEALTH DIAGNOSIS BY CATEGORY

See manual for example of diagnoses within each category.

	0. No	1. Yes
a. Delirium, dementia, and amnestic and other cognitive disorders	○	○
b. Schizophrenia and other psychotic disorders	○	○
c. Mood disorder	○	○
d. Anxiety disorder	○	○

SECTION O. MEDICATIONS

1. ALLERGY TO ANY DRUGS

○ 0. No known drug allergies ○ 1. Yes

2. PHYSICIAN REVIEWED PERSON'S MEDICATIONS AS A WHOLE IN LAST 180 DAYS OR SINCE LAST ASSESSMENT

- ○ 0. Discussed with at least one physician (or no medication taken)
- ○ 1. No single physician reviewed all medications

3. ADHERENCE WITH MEDICATIONS PRESCRIBED BY PHYSICIAN

- ○ 0. Always adherent
- ○ 1. Adherent 80% of time or more
- ○ 2. Adherent less than 80% of time, including failure to purchase prescribed medications
- ○ 8. No medications prescribed

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[CODE FOR LAST 3 DAYS UNLESS OTHERWISE SPECIFIED]

4. LIST OF ALL MEDICATIONS

List all active prescribed medications of the last 3 days, and any non-prescribed (over the counter) medications taken in the **last 3 days**.
[NOTE: Where possible, use computerized records. Hand enter only when absolutely necessary.]

For each drug, record:

a. Name - Record the name of the medication

b. Dose - A number such as 0.5, 5, 150, 300 [NOTE: Never write a zero by itself after a decimal point (X mg). Always use a zero before a decimal point (0.X mg)]

c. Unit

gtts	drops	mcg	microgram	ml	millilitre	%	percentage
gm	gram	mEq	milliequivalent	oz	ounce		units
L	litre	mg	milligram		puffs	OTH	other

d. Route of administration - Code using the following list:

PO	by mouth	IV	intravenous	TOP	topical	ET	enteral tube
SL	sublingual	Sub-Q	subcutaneous	IH	inhalation	TD	transdermal
IM	intramuscular	REC	rectal	NAS	nasal	OTH	other

e. Frequency - Code the number of times per day, week, or month the medication is administered using the following list:

Q1H	every hour	Daily	once daily	Q2D	every other day	5W	5 times weekly
Q2H	every 2 hours	BID	2 times daily (includes every 12 hours)	Q3D	every 3 days	6W	6 times weekly
Q3H	every 3 hours			Weekly	once every week	1M	monthly
Q4H	every 4 hours	TID	3 times daily	2W	2 times weekly	2M	twice every month
Q6H	every 6 hours	QID	4 times daily	3W	3 times weekly	OTH	other
Q8H	every 8 hours	5D	5 times daily	4W	4 times weekly		

f. PRN - 0. No 1. Yes

g. Computer-entered drug code [Example Canada - DIN]

	a. **Name** (continue on reverse of form if necessary)	b. **Dose**	c. **Unit**	d. **Route**	e. **Freq.**	f. **PRN** No	Yes	g. **Computer-entered drug code**
1						○	○	
2						○	○	
3						○	○	
4						○	○	
5						○	○	
6						○	○	
7						○	○	
8						○	○	
9						○	○	
10						○	○	
11						○	○	
12						○	○	

(Add lines as necessary for other drugs taken)

SECTION P. ASSESSMENT INFORMATION

SIGNATURE OF PERSON COORDINATING/ COMPLETING THE ASSESSMENT

a. **Signature**

b. **Date assessment signed as complete**

a) Year

○ 1	○ 8	○ 1	○ 1
● 2	○ 9	○ 2	○ 2
	● 0	○ 3	○ 3
		○ 4	○ 4
		○ 5	○ 5
		○ 6	○ 6
		○ 7	○ 7
		○ 8	○ 8
		○ 9	○ 9
		○ 0	○ 0

b) Month

○ January	○ July
○ February	○ August
○ March	○ September
○ April	○ October
○ May	○ November
○ June	○ December

c) Day

○ 1	○ 7	○ 12	○ 17	○ 22	○ 27
○ 2	○ 8	○ 13	○ 18	○ 23	○ 28
○ 3	○ 9	○ 14	○ 19	○ 24	○ 29
○ 4	○ 10	○ 15	○ 20	○ 25	○ 30
○ 5	○ 11	○ 16	○ 21	○ 26	○ 31
○ 6					

Appendix B: interRAI Intellectual Disability Supplement

inter*RAI*-ID Supplement

SUPPLEMENT

1. NUMERIC IDENTIFIER

a. Client's Health Card Number

0	○	○	○	○	○	○	○
1	○	○	○	○	○	○	○
2	○	○	○	○	○	○	○
3	○	○	○	○	○	○	○
4	○	○	○	○	○	○	○
5	○	○	○	○	○	○	○
6	○	○	○	○	○	○	○
7	○	○	○	○	○	○	○
8	○	○	○	○	○	○	○
9	○	○	○	○	○	○	○

b. Birthdate

a) Year				**b) Month**	**c) Day**		
○ 1	○ 8	○ 0	○ 0	○ January	○ 1	○ 12	○ 22
○ 2	○ 9	○ 1	○ 1	○ February	○ 2	○ 13	○ 23
	○ 0	○ 2	○ 2	○ March	○ 3	○ 14	○ 24
		○ 3	○ 3	○ April	○ 4	○ 15	○ 25
		○ 4	○ 4	○ May	○ 5	○ 16	○ 26
		○ 5	○ 5	○ June	○ 6	○ 17	○ 27
		○ 6	○ 6	○ July	○ 7	○ 18	○ 28
		○ 7	○ 7	○ August	○ 8	○ 19	○ 29
		○ 8	○ 8	○ September	○ 9	○ 20	○ 30
		○ 9	○ 9	○ October	○ 10	○ 21	○ 31
				○ November	○ 11		
				○ December			

2. DATE

a) Year	**b) Month**	**c) Day**		
● 2005	○ January	○ 1	○ 12	○ 22
	○ February	○ 2	○ 13	○ 23
	○ March	○ 3	○ 14	○ 24
	○ April	○ 4	○ 15	○ 25
	○ May	○ 5	○ 16	○ 26
	○ June	○ 6	○ 17	○ 27
	○ July	○ 7	○ 18	○ 28
	○ August	○ 8	○ 19	○ 29
	○ September	○ 9	○ 20	○ 30
	○ October	○ 10	○ 21	○ 31
	○ November	○ 11		
	○ December			

3. ONE-TO-ONE CARE OR SUPERVISION

Amount of one-to-one direct care or supervision received. Code for most intensive day in the last 3 days.

- ○ 0. None
- ○ 1. Up to one hour
- ○ 2. Between 1 and 4 hours
- ○ 3. Between 4 and 8 hours
- ○ 4. Between 8 and 16 hours
- ○ 5. Between 16 and 24 hours

4. EXPECTED CHANGE IN NEED FOR ONE-TO-ONE DIRECT CARE OR SUPERVISION UPON COMMUNITY PLACEMENT

- ○ 0. No change
- ○ 1. Need for one-to-one direct care or supervision expected to increase
- ○ 2. Need for one-to-one direct care or supervision expected to decline

5. SIGNATURE OF PERSON COMPLETING THE SUPPLEMENT

a. **Signature**

b. **Role in the interRAI-ID study**

- ○ 0. Staff Assessor
- ○ 1. Site Coordinator or Lead

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Appendix C: Location and Coding of interRAI ID items

Location and Coding of inter*RAI* ID 1.0, 2.0, and 3.0 items

	Community Sample		Facility Sample	
Outcome	**inter*RAI ID* 1.0**	**inter*RAI* ID 2.0**	**inter*RAI* ID 3.0**	**Re-coding**
Pica	**I9** In last 30 days 0=No 1=Yes	**L5i** 0=Not present 1=Present but not exhibited in last 3 days 2=Exhibited on 1-2 of last 3 days 3=Exhibited daily in last 3 days	**L5i** 0=Not present 1=Present, but not exhibited in last 3 days 2=Exhibited on 1-2 of last 3 days 3=Exhibited daily in last 3 days	1=Present 0=Not present

	Community Sample		Facility Sample	
Demographic Characteristics	**inter*RAI ID* 1.0**	**inter*RAI* ID 2.0**	**interRAI ID 3.0**	**Re-coding**
Gender	A2 1=Male 2=Female	A2 1=Male 2=Female	A2 1=Male 2=Female	1=Male 0=Female
Age	N/A	N/A	N/A	Assessment reference date – Birthdate/365.25
Length of Stay	N/A	N/A	N/A	Assessment reference date–Date stay began/365.25
Nature of Intellectual Impairment	C1 0=Mental Retardation 1=Down's syndrome 2=Autism or autism spectrum disorder 3=Turner's syndrome 4=Fetal alcohol syndrome 5=Rett's syndrome 6=Tourette's syndrome 7=Congenital rubella 8=Other	B5 1=Mental Retardation 2=Down's syndrome 3=Autism or Autistic spectrum disorder B5B 4='Angelman syndrome' 5='Asperger syndrome' 6='Congenital hypothyroidism' 7='Congenital rubella' 8='Cri du chat noir' 9='De Lange syndrome' 10='Fragile X syndrome' 11='Hunter syndrome' 12='Hurler syndrome' 13='Klinefelter syndrome' 14='Lesch-Nyhan syndrome' 15='Neuro-fibromatosis syndrome' 16='Noonan syndrome' 17='Phenylketonuria'	B4 1=Cause unspecified 2=Down's syndrome 3=Autism or Autistic spectrum disorder 4=Other B4B 4='Angelman syndrome' 5='Asperger syndrome' 6='Congenital hypothyroidism' 7='Congenital rubella' 8='Cri du chat noir' 9='De Lange syndrome' 10='Fragile X syndrome' 11='Hunter syndrome' 12='Hurler syndrome' 13='Klinefelter syndrome' 14='Lesch-Nyhan syndrome' 15='Neuro-fibromatosis syndrome' 16='Noonan syndrome' 17='Phenylketonuria'	1=Cause unspecified (Mental Retardation) 2=Down's syndrome 3=Autism or Autistic spectrum disorder 4=Other

		18='Prader-Willi syndrome' 19='Rett disorder' 20='Sanfilippo syndrome' 21='Smith-Magenis syndrome' 22='Sturge-Weber syndrome' 23='Tourette disorder' 24='Turner syndrome' 25='Tuberous sclerosis' 26='Williams syndrome' 99='Other';	18='Prader-Willi syndrome' 19='Rett disorder' 20='Sanfilippo syndrome' 21='Smith-Magenis syndrome' 22='Sturge-Weber syndrome' 23='Tourette disorder' 24='Turner syndrome' 25='Tuberous sclerosis' 26='Williams syndrome' 99='Other';	
Documented Severity of Intellectual Disability	C2 1=Mild 2=Moderate 3=Severe 4=Profound 5=Unknown	B6 0=No intellectual impairment 1=Borderline 2=Mild 3=Moderate 4=Severe 5=Profound 8=Not documented	B5 0=No intellectual impairment 1=Borderline 2=Mild 3=Moderate 4=Severe 5=Profound 8=Not documented	*Note Recode for Community Sample only 1=Borderline/Mild 2=Moderate 3=Severe 4=Profound 5=Undocumented (Unknown) No intellectual impairment set to missing

Location and Coding of inter*RAI* ID 3.0 items (Facility Sample)

Demographic Characteristics	Location	Re-coding
Age at which person left family home	**B6**	88 (N/A) and 99 (unknown) set to missing
Number of Years (lifetime) spent in an institutional Setting for persons with intellectual disability	**B7**	99 (unknown) set to missing

Activity Preferences and Involvement	Location	Re-coding
Cards, games, or puzzles Collecting Computer activity Conversing Crafts or arts Exercise or sports Gardening or plants Helping others Music or singing Pets Reading, writing, crossword puzzles Spiritual or religious activities Trips or shopping Walking or wheeling outdoors Watching TV or listening to radio	**C4a to C4o** 0=No preference 1=No preference, involved in last 3 days 2=Preferred, not involved in last 3 days 3=Preferred, regularly involved but not in last 3 days 4=Preferred, involved in last 3 days	1=Involvement (1,3,4) 0=No involvement (0,2)
Sense of Involvement		
At ease interacting with others At ease doing planned or structured activities Pursues involvement in activities of residential setting or community	**C5a** **C5b** **C5c** 0=No 1=Yes	N/A

Psychosocial Well-being and social supports	Location	Re-Coding
Strong and Supportive relationship with family	**D7** 0=No 1=Yes	N/A
Participation in social activities of long-standing interest Visit with long-standing social relation or family member Other interaction with long-standing social relation or family member Overnight stay of 1 or more nights at home of family member or long-standing social relation	**D9a** **D9b** **D9c** **D9d** 0=Never 1=More than 30 days ago 2=8-30 days ago 3=4-7 days ago 4=In last 3 days 8=Unable to determine	1=participation in last 30 days (2,3,4) 0=participation more than 30 days ago (0,1) 8 set to missing
Conflict with or repeated criticism of family or friends Conflict with or repeated criticism of other clients/staff Family/close friends are persistently hostile toward person	**D8a** **D8b** **D8c** 0=No 1=Yes	N/A

Communication	Location	Re-coding
Communication method	**G1** 1=Verbal 2=Non-verbal	1=Non-verbal 0=Verbal
Making self understood	**G2** 0=Understood 1=Usually understood 2=Often understood 3=Sometimes understood 4=Rarely/never understood	N/A
Ability to understand others	**G3** 0=Understands 1=Usually understands 2=Often understands 3=Sometimes understands 4=Rarely/never understands	N/A

Gastrointestinal Health Conditions	Location	Re-coding
Acid reflux Constipation Dry mouth Increase or decrease in normal appetite Vomiting Diarrhea Nausea	**I2d** **I2e** **I2g** **I2i** **I2k** **I2f** **I2j** 0=Not present 1=Present, but not exhibited in last 3 days 2=Exhibited on 1 of last 3 days 3=Exhibited on 2 of last 3 days 4=Exhibited daily in last 3 days	1=present (1,2,3,4) 0=not present (0)
Gastrointestinal Disorder	**N1fa to N1za** **N1aaa to N1mma** Open-ended text	Mineral Deficiency: 1=present 0=not present 'ANEMIA' 'ANAEMIAS' 'THALASSAEMIAS' 'IRON DEFICIENCY' 'IRON DEFICIENCY ANEMIA' 'IRON DEFICIENTY ANEMIA' 'HISTORY OF IRON DEFICIENCY' 'MELENA AND ANEMIA' 'SEVERE ANEMIA' 'MACROCYTIC ANEMIA' 'HISTORY OF IRON DEFICIENCY' Gastrointestinal Disease: 1=present 0=not present

Mobility	Location	Recoding
Distance wheeled self	**J2** 0=Wheeled by others 1=Less than 5 metres 2=5-49 metres 3=50-99 metres 4=100+ metres 8=Did not use wheelchair	1=Wheelchair (0,1,2,3,4) 0=No wheelchair (8)
Walking: Performance	**J1e** 0=Independent 1=Set-up help only 2=Supervision 3=Limited assistance 4=Extensive assistance 5=Maximal assistance 6=Total dependence 8=Activity did not occur	0=Independent (0) 1=Set-up help to supervision (1,2) 2=Limited assistance to total dependence (3,4,5,6) 8 set to missing

Challenging behaviours	Location	Re-coding
Wandering Verbal abuse Physical abuse Socially inappropriate or disruptive behaviour Inappropriate public sexual behaviour or public disrobing Resists care Self-injurious behaviour Destructive behaviour Outburst of anger	**L5a** **L5b** **L5c** **L5d** **L5e** **L5f** **L5g** **L5h** **L5j** 0=Not present 1=Present, but not exhibited in last 3 days 2=Exhibited on 1-2 of last 3 days 3=Exhibited daily in last 3 days	1=Present (1,2,3) 0=Not present (0)
Rumination Polydipsia	**K4** **K5** 0=No 1=Yes	N/A

Interventions	Location	Re-coding
Self-care training skills	**M6a**	1=Offered (1,2,3,4) 0=Not offered (0)
Community skills training	**M6b**	
Social skills training	**M6c**	
Cognitive skills training	**M6d**	
Education on special topics	**M6e**	
Behaviour management	**M6f**	
Sensory Stimulation programs	**M6g**	
	0=No services or program of this type offered 1=Offered, but refused 2=Not received, but scheduled to start within next 30 days 3=Received 8-30 days ago 4=Received in last 7 days	

Psychiatric Diagnosis	Location	Recoding
Delirium, dementia, and amnestic and other cognitive disorders	**N2a**	N/A
Schizophrenia and other psychotic disorders	**N2b**	
Mood disorder	**N2c**	
Anxiety disorder	**N2d**	
	0=No 1=Yes	

Medications	Location	Recoding
List of Medications	**O4a1 to O4a28** Open-ended text	Classes of antipsychotic medication 1=Present 0=Not present

Appendix D: Focus Group Guide

Introduction

First, I’d like to thank everyone for giving us their time to come here today to help us. My name is Melody Ashworth and I am a student at the University of Waterloo. Today, I will be asking you questions about your experiences and opinions regarding caring for a person with pica. As you know, this is a focus group so don’t hesitate to expand on points that you think are important or that you think I should know. This work is part of my Masters of Science degree in the Department of Health Studies and Gerontology at the University of Waterloo, under the supervision of Dr. Hirdes. Our goal is to gain a better understanding of what it’s like to care for someone with pica. Specifically, I will be asking you three main questions: 1) how much time is involved in caring for someone with pica, 2) what resources are required to care for someone with pica, and 3) what resources do you desire to provide the best care for someone with pica. Your experience and insight are extremely valuable, as there is currently very little in-depth information on this topic. Your participation may help in the long-term in assisting service providers to plan and provide the best available supports to people in the same situation as you are in. Once again, I’d like to thank you for your participation today.

Your participation in this focus group is completely voluntary and you may decline to answer any of the questions at any time. All information you provide is completely confidential and your name and the name of your son/daughter or the name of the person you support will not be mentioned in my thesis or in any publication relating to this work. Given the group format of this session I ask that you please keep in confidence the information that other participants provide and information that could potentially identify a participant and the person(s) that they support.

In terms of how this might work, I thought that we could begin by introducing ourselves using a pseudonym for yourself and for the person(s) you support to ensure confidentiality of everyone. We will spend about an hour and a half talking about pica. There are refreshments available. Please feel free to get up and help yourself at any time.

You’ll notice the tape recorder on the table. Please do not be self-conscious. We are recording the meeting to ensure that we record the information accurately. In addition, you may notice us taking notes from time to time. Again, we are doing this to make sure that we a recording everything you are saying accurately.

Does anyone have any questions before we begin?

With everyone’s permission, I am going to start the tape recorder now.

So, let’s start by going around the table and introducing ourselves. Could everyone tell us their pseudonym for themselves and for the person(s) they support, and how long have they been supporting person(s) with pica.

Part 1: General Attitudes

1a) Now, I’d like to ask each person about their experiences of caring for an individual(s) with pica?

- What happens in a good day?
- What happens in a bad day?
- Ask for examples

Part 2: Time

2a) How much time do you spend in daily activities together?

2b) What kinds of activities does the person or individuals enjoy?

2c) How much time do you spend in a day managing the person’s pica behaviour?

- How often does that happen?
- What is the staff to client ratio?

Part 3: Approaches for Managing Pica

3a) What approaches do you use to deal with the person’s pica?

- Managing the environment—the removal or locking up objects
- Provision of safe “mouthing toys”
- Provision of food/drinks
- Not leaving them alone or unoccupied
- Blocking by use of verbal prompts (“stop”) or physically preventing them from ingesting items
- Redirection to other activities, or to food
- Providing choices or rewards when pica does not occur---toys, food, access to things the person enjoys
- Teaching them what is and isn’t edible
- Punishment—oral hygiene routines etc. contingent on pica
- Self-protective devices
- Brief physical restraint (e.g., holding the person’s arms at the side of their body for a few seconds)
- Medications

3b) What strategies work well for the person?

- Ask for examples

- Why is that?

3c) What strategies do not work well for the person?

- Ask for examples

- Why is that?

Part 4: Resources

4a) What resources do you use right now to help you deal with pica?

- Personal Support worker
- Respite care (for families)
- Behavioural support plan
- Professional help (e.g., behavioral therapist)
- Informal supports (family, friends)

4b) What other approaches are available that you know about or you can access?

4c) Are there additional supports you desire or need that would help in managing pica?

Part 5: Challenges

5a) What challenges or barriers make it difficult to reduce pica?

- Financial
- Not enough staffing
- Friends, other people in his/her life

5b) What challenges or barriers make it difficult to achieve better quality of life for persons with pica?

5c) What problems have arisen because of pica?

- Physical (medical problems)
- Social consequences (isolation, less likely to engage in meaningful activities)
- Strained relationships
- Feeling overwhelmed

5d) Do you have difficulty accessing medical or other supports, as needed? Please expand.

Part 6: Caregiver Workload

6a) Overall, how does pica affect you as a caregiver? Also, how does it affect other caregivers or family members?

- Ask for examples
- Both positive and negative experiences

Part 7: Wrap-Up

7a). Is there anything else you would like to tell me about your experiences of caring for someone with pica?

Appendix E: Participation Information Letter

[Date]
[Name]
[Title]
[Address]

Dear Mr./Ms______________________,

This letter is an invitation to participate in a study I am conducing as part of my Master of Science degree in the Department of Health Studies and Gerontology at the University of Waterloo, under the supervision of Dr. John Hirdes.

The purpose of my study is to gain a better understanding of what its like for front-line staff to support persons with an intellectual disability (ID) who engage in pica behaviour (the ingestion of non-food substances). Specifically, I am interested in the strategies and time involved in supporting someone with pica. Further, I am interested in the resources that you desire in order to provide the best possible support. Your experience and insight are extremely valuable, as there is currently very little in-depth information on this topic. Your participation may help in the long-term in assisting service providers to plan and provide the best available supports to people in the same situation as you are in.

Participation in this study is voluntary. It will involve a short background questionnaire and a focus group consisting of six people who have a similar experience of supporting person(s) with ID and pica. The focus group will take approximately two hours, and will take place at the University of Waterloo (or a mutually agreed upon location). With your permission the focus group discussion will be audio-tape recorded and later transcribed for analysis. I will send you a summary of the main themes that emerge from the focus group approximately two months after the focus group and ask for your verbal or written feedback to ensure their accuracy.

You may decline to answer any of the focus group questions if you wish, and you may decide to withdraw from this study at any time. Pseudonynms will be used by you and the other focus group participants to ensure confidentiality during the discussion. Further, any quotations will be kept anonymous and you will not be identified by name in the report that the researcher produces. All the information you provide is considered completely confidential by the researchers and neither your name nor the names of the names of the persons in your care will be mentioned in my thesis or any publication relating to this study. The information collected from this session, including audiotapes, transcripts and notes will be kept for a period of five years in a secured location at Homewood Research Institute, after which it will be destroyed. Dr. John Hirdes is the Scientific Director of the Homewood Research Institute at Homewood Health Centre in Guelph.

You will be compensated for your travel at 35.7 cents per kilometer; however, you will not be paid for participating in this study. At the end of my research study you will be provided with a final summary of the main findings.

I would be very grateful if you decide to participate in this study as we believe that your participation will contribute to furthering our knowledge of the support needs and the development of best practices for persons with ID and pica. This project has been reviewed by, and received ethics clearance from the Office of Research Ethics at the University of Waterloo. If you have any questions regarding this study, or if you are interested in participating, please contact me at (519) 824-1010 ext. 2462 or by e-mail at mkashwor@ahsmail.uwaterloo.ca, or you may contact my supervisor, Dr. John Hirdes at (519) 888-4567 ext. 2007 or by e-mail at hirdes@healthy.uwaterloo.ca. If you have concerns about your involvement in this study, you may contact Dr. Susan Sykes at the Office of Research Ethics at (519) 888-4567, ext. 6005.

I will be following up this letter with a phone call to ask if you will be willing to participate in this study. I look forward to speaking with you at this time.

Sincerely,
Melody Ashworth
M.Sc. Candidate
Department of Health Studies and Gerontology
University of Waterloo
200 University Avenue West
N2L 3G1

Appendix F: Follow-Up Telephone Script

Hello Mr./Ms____________________, my name is Melody Ashworth and I'm a Master's student in the Department of Health Studies and Gerontology at the University of Waterloo. I sent you a letter last week describing a study that I am conducting that is looking at the experiences that caregivers have in supporting persons with an intellectual disability who have pica. Did you receive the letter?
[If no, tell them that I'll resend it immediately and the read contents of participation information letter]
[If yes], So, just to review, I am conducting this study for my Master's thesis. Participation in the study would involve participating in a focus group consisting of six people. The focus group would take approximately two hours during which time I would ask you about your experiences, opinions, and the strategies that you use regarding supporting person(s) with ID and pica. With your permission, the focus group would be audiotaped and I would also ask you to complete a brief questionnaire. A couple of months after the focus group I will also ask you for your feedback on the main themes that emerge from the study. You will be compensated for your travel; however, you will not be paid for participating in this study.
Do you have any questions about the study? Do you think you might be interested in participating?
[if no] Thank you for your time. [If yes] Thank you! Here are some possible dates and times, [locations] for a focus group. I'm looking forward to meeting you.

Appendix G: Background Questionnaire

Code number:____________

1. What is your position/job title?

2. How long have you supported persons with pica? [Huronia Regional Centre only]

3. How long have you know this person (persons that you support with pica)? [Community only]

4. How well do you feel you know this person? [Community only]

5. What types of supports do you provide to the person [persons with pica]? This includes both direct (front-line) and indirect supports (management of staff, training, creating individualized support plans, advocating for services)

6. Have you ever had experience in this area (i.e., dealing with pica) prior to this caregiving experience?

Appendix H: Consent Form for Participation

Title of Study: Caregivers' Perspectives on Supporting Adults with an Intellectual Disability and Pica: Resource Implications

I agree to participate in a study conducted by Melody Ashworth of the Department of Health Studies and Gerontology at the University of Waterloo, under the supervision of Dr. John Hirdes.

I agree to participate in a 2-hour focus group. I give permission for the focus group to be audiotaped and transcribed and for the researcher to take notes during the interview. I give permission to complete a short background questionnaire. I also give permission for the researcher to contact me after the focus group to ensure the accuracy of the main themes that emerge from the focus group. I will select pseudonyms to use instead of my real name and the name(s) of the person(s) that I support in order to ensure that my responses remain completely confidential. I was informed that I will not identified by name in the researcher's thesis, or in any report or publication resulting from this and that all information that I provide will be confidential and all materials will be kept in a secure location and destroyed in five years after all publications related to this research have been completed.

I have made this decision based on the information I read in the information letter and I have had the opportunity to ask further details about the study. I am aware that my consent may be withdrawn at any time during the study without penalty by notifying the researcher. I also understand that this project has been reviewed by, and received ethics clearance from the Office of Research Ethics at the University of Waterloo, and that I may contact Dr. Susan Sykes at (519) 888-4567, ext. 6005 if I have any concerns or questions that arise from my involvement in this study. I may also contact Melody Ashworth at (519) 824-1010, ext. 2462 or mkashwor@ahsmail.uwaterloo.ca, and Dr. John Hirdes at (519) 888-4567 ext. 2007 or hirdes@healthy.uwaterloo.ca

Participant's Name:____
Participant's Signature:____
Date:____
Witness's Name:____
Witness's Signature:____
Date:____

Appendix I: Participation Feedback Letter and Summary of Main Themes

[Date]
[Name]
[Title]
[Address]

RE: Study on caregivers' perspectives on supporting adults with an intellectual disability and pica: resource implications

Dear Mr./Ms._____________________________________,
I would like to thank you for your participation in this study. I enjoyed meeting you and I appreciate the time you gave to this study; your input was invaluable. The focus groups that I have conducted have yielded interesting, in-depth information regarding the strategies and resource needs of adults with an intellectual disability and pica.

As mentioned in the focus group, I would appreciate your feedback on the main themes that have emerged across the two focus groups. Essentially, I would like to know whether you think these themes seem appropriate and whether you would like to add anything, either specific or general. Please find attached an outline of the main themes. You may e-mail, mail or call me with your comments at the addresses and numbers below.

Please be assured that any information pertaining to you as an individual participant and information concerning persons that you support will be kept confidential. Once all the data are analyzed for the project, I plan on sharing this information with the research community through presentations, and journal articles.

If you would like a summary of the final results, please let me know and I will send you this information when the study is completed.

As with all University of Waterloo projects involving human participants, this project was reviewed by, and received ethics clearance from the Office of Research Ethics at the University of Waterloo. If you have any questions or concerns about your participation in this study, please contact Dr. Susan Sykes at the Office of Research Ethics at (519) 888-4567, ext. 6005.

Sincerely,

Melody Ashworth
Department of Health Studies and Gerontology
University of Waterloo
200 University Avenue West
N2L 3G1
E-mail: mkashwor@ahsmail.uwaterloo.ca
Telephone: (519) 885-3877 (home), (519) 824-1010 ext. 2462 (Homewood Research Institute)

Caregivers' perspectives on supporting adults with an intellectual disability and pica: resource implications

Summary of Main Themes

Several preliminary main themes and sub-themes emerged from the analysis from two focus groups. A total of ten staff took part in this study. Four staff from Huronia Regional Centre (HRC), an institution for persons with intellectual disability, participated in one focus group. The second focus group consisted of six community staff from four developmental service agencies in southwestern Ontario.

I am in the process of describing these in detail and interpreting them. The results will then be related to the scientific literature. I am using a qualitative methodology, therefore the idea is to gather rich, in-depth information to improve our understanding of your experiences, rather than collect statistical information.

The support needs of individuals with an intellectual disability and pica are influenced by several factors. These were grouped into factors that facilitated or constrained the support of persons with pica.

The support of persons with pica is facilitated by the following factors:

1. ***Prevention***: Prevention was the most consistently reported intervention used to manage pica behaviour in both settings and was felt to be the most effective. This took the form of "pica-proofing" the living environment by removing or locking up potential pica items and is implemented on a daily/routine basis in order to reduce the risk of pica. These pica proofing routines appear to be internalized by staff to such an extent that they become automatic. Many staff reported that they worried about the safety of the person(s) they supported (that it was always in the back of their mind) and whether they had locked up everything and checked the environment while they were on shift.

2. ***Knowing the individual:*** Staff's familiarity with the individual(s) they support is another important factor that is helpful in managing pica. By having knowledge about each individual, staff stated they felt more empowered to prevent and manage pica. Knowing the individual was central in three main aspects: knowing the desired items that they preferred, knowing the severity of the pica, and knowing that each individual is unique with respect to treatment. Staff from both settings expressed a belief that interventions should be tailored to each individual. This was supported by the diversity of techniques that were used and the fact that particular techniques worked for some cases but not for others.

3. ***Circle of Support:*** A good circle of support—a network of family, staff, and professionals that are responsible for the individuals' well-being—was identified by staff as helpful in managing pica. The institution has the most comprehensive circle of support as staff have access to medical and behavioural support on-site. Access to services is variable across community agencies and group homes. Although half of the staff reported having problems accessing and/or getting a response from physicians, the community staff who had positive relations with their physicians were able to be linked to other specialists. In terms of professional supports, only a minority of community staff reported that they had made connections to special clinical supports or to other medical specialists. A final factor related to the circle of support was staff consistency. A consistent approach to managing pica was facilitated by having good staff relations, good communication between staff, and by having protocols in place.

The support of persons with pica is hindered by the following factors:

1. ***Inadequate staff support:*** All institutional staff and the majority of community staff reported that they needed more intensive staffing. The consequences of inadequate supervision are myriad, including that persons with pica participate in fewer recreational activities and community outings, and the use of more intrusive measures, such as mechanical restraints. As well, staff in the institution noted that increased supervision is needed because pica is often a hidden or passive behaviour and residents with more overt behaviour will often take precedence. In addition, the focus groups revealed that many individuals with pica have other challenging behaviours that make them challenging to support.

2. Functioning level of the individual: A major barrier identified by many participants was that the person(s) they supported were very low functioning. Consequently, the prevalent feeling was that it was difficult to change the behaviour because the individuals do not understand the dangers of pica and further they are unable to follow instructions or to learn more adaptive behaviours. Also, communication impairments make it difficult for staff to monitor the health status of the individual(s) they support. Half of the community and institutional staff expressed frustration that the individuals they support have very limited interests, making it difficult to engage them in alternative activities. Consequently, staff on the whole felt that there are few alternatives to managing pica except for prevention.

3. Lack of Knowledge: All staff indicated that there was a lack of knowledge regarding the function and treatment of pica. Staff acknowledged that they did not understand the causes of pica and felt there was little information for them to access or to help them manage the behaviour. About half of the community staff also did not have knowledge of the service system and how to connect with specialized clinical services (e.g., behaviour therapists, psychologists), which may contribute to the persistence of the behaviour. A number of community staff suggested that agencies should collaborate so that others can share their ideas on how to manage pica. The community at large is also not aware of pica and its complications. Some community staff reported the stigmatization they felt while in the community with a person with pica. Staff from the institution were predominantly concerned with outsiders from the community visiting the institution who did not have knowledge of pica and its complications and as such they focused their efforts on informing others about pica. In general, lack of knowledge makes it difficult for staff to manage pica and to access and provide proper services.

Barriers specific to the community were:

Circle of Support

- Staff relations: lack of cohesion among full-time and part-time staff
- Part-time staff not following protocols
- Access and/or response from physicians

Lack of Knowledge

- Knowledge of the developmental service system and interest in seeking out specialized clinical support services (e.g., behaviour therapists, psychologists, psychiatrists)
- Interagency communication is not well established and collaboration across the service system is limited with respect to sharing case examples and interventions for pica

Barriers specific to the institution were:

Inadequate Staff Support:

- Low staff to client ratios
- Large number of individuals with pica; thus block or group strategies take precedence over individualized strategies for managing pica