Supporting and Maximizing Communication Between Individuals with Intellectual Disabilities and Health Care Providers

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Child and Youth Studies

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ABSTRACT

The goal of the present study was to examine the barriers to access in health services faced by individuals with intellectual disabilities (ID), as well as the nature of communication between people with ID and those who are directly involved in supporting their health and well being. The study included in-depth interviews with five adults who have been identified as having ID and are supported by a community agency, five community agency support staff and four physicians who are specialists in supporting people who have ID. A qualitative content analysis approach facilitated the comparative exploration of key themes that each participant group saw as positive or negative influences on health care access and on effective health care communication. Themes drawn from the findings emphasize the unique roles each of these groups plays within the dialogical framework of the health care encounter. Of particular importance to informants was the issue of people with ID being seen as full participants in their own health care who, like all people, are unique individuals and not simply members of an identified or marginalized group. Participants across groups emphasized the need for the health care recipient to be known as an individual who is an expert in her/his own health and well being and, therefore, entitled to full participation with the support of but not control by others.
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BACKGROUND AND SIGNIFICANCE OF STUDY

People with intellectual disabilities (ID) have physical and mental health problems that differ from those of the general population. As well, people with ID encounter barriers in access to health care services that prevent them from receiving the health services they need. Both of these factors give rise to inequalities and inequities in health determinants and health outcomes. A major barrier to accessible health care is inadequate communication between health care providers and persons with ID, who may or may not be accompanied by a support person. The issue of striving for effective health care communication is not unique to this population; it is something for which we all hope. What is unique, and therefore requiring thoughtful investigation, is the complexity of the communicative process among health care professionals, people who have ID and their support persons (Ziviani, Lennox, Allison, Lyons, & Del Mar, 2004). As Lennox and Edwards (2001, p.20) state, "people with an intellectual disability are not passive players in the dynamics of their health and well-being". In order to ensure that this statement holds true, people with ID must have the opportunity to have greater control of their health care determinants and be supported by a health care environment that is equipped to hear them. The focus of this study was on the investigation of the nature of and the key elements needed to facilitate effective communication among health care providers, people with ID and their community support workers.

While it must be acknowledged up front that the following review of the literature opens from a very broad based perspective, its purpose for doing so is to provide an understanding of past research involving barriers to health care access and to gain an understanding of how communication is situated within the larger context of health and
wellbeing for individuals with ID. This in turn illustrates the impact that positive or negative health care communication encounters can have on the lives of individuals with ID.

REVIEW OF THE LITERATURE

It is universally accepted that all people are entitled to have an opportunity to be healthy. Health is not a merit good (Hancock, 1999); all people are entitled to an equal chance at health. The right to health is described in the UN Constitution and international human rights treaties as "the right to the highest attainable standard of health" (UNHCRC, 1976, article 12). The aim of our health care system in Canada is to support that right by providing health promotion and illness prevention as well as diagnosis, treatment, rehabilitation and palliative care.

The growing body of international literature on the health of people with ID points to their experiencing a larger number of health needs as compared to the general population. Far too often, these health needs are described as potentially correctable but are unrecognized and therefore unmet (Beange, Lennox, & Parmenter, 1999). Lennox and Kerr (1997) point out and the information contained within this review of the literature supports the notion that research in the area of meeting health care needs of people with ID consistently reflects three serious problems: “1) untreated but treatable, simple medical conditions, 2) untreated, specific health issues related to the individual’s disability, and 3) a lack of participation in general health promotion and screening programs, such as blood pressure screening” (Kerr, 2004, p. 203).

In an epidemiological population sample of 202 adults with ID in Sydney, Australia, Beange, McEllduff and Baker (1995) concluded that, on physical examination,
study participants had, on average, five serious medical disorders but that only half of these conditions had been detected or were being treated. Not only do health needs present in greater number in people who have ID, but the patterns and types of health needs also differ from those of the general population (Cooper et al., 2006). Some health needs are co-morbid conditions that are unrelated but can occur alongside a diagnosis of an intellectual disability and have a negative impact on health (e.g., cancer or hypertension) (Krahn, Hammond, & Turner, 2006). Some are secondary conditions, which refer to those conditions that a person with a pre-existing intellectual disability experiences at a higher rate than the rest of the population, and are generally seen as being preventable (Simeonsson & Leskinen, 1999). Examples might include pressure ulcers, bowel obstruction or depression (Krahn et al., 2006).

It is increasingly being recognized that the differences or disparities in health among people with ID as compared to the general population may be directly attributable not only to genetic and biological determinants but also to additional negative determinants that give people with ID a decreased opportunity for health. One of these determinants is health care that is less accessible to people with ID than to the general population. The need, as well as the right, of people with intellectual disabilities to have good and barrier-free access to health care is clearly evident, and positive policy statements and guidelines have sprung forth world wide in recent years to address this fact (Beange, Lennox, & Parameter, 1999; Department of Health, 2001; U.S. Public Health Service, 2002; Sullivan et al., 2006). Unfortunately, there continue to be barriers that prevent these policies from being carried out in practice, thereby hindering health needs from being identified early, and, subsequently, from being met.
In health care communication, the exchange that takes place between providers and people with ID has the potential to act as a tremendous barrier, or to contribute as a positive enabler in providing access to health care for people with ID. A breakdown in communication means that people with ID and health care providers are unable to establish an effective interface, and what results are problems in understanding from both perspectives (Matthews, 2002). Van der Gaag (1998) states that "there can be little doubt that effective communication is of crucial relevance to the health and well being of people with intellectual disabilities... What is much less certain is how 'effective communication' is defined, still less how it can be maximized" (p.1). Effective communication is integral to the provision of health care that responds to the needs of people with ID. In addition, communication needs to be supported by strategies and values that empower people to recognize and express needs, and to recognize and express their right to full opportunity within the health care system (Byng, Farrelly, Fitzgerald, Parr, & Ross, 2003).

Conceptualizing Health

The concept of health is the same for people with and without intellectual ID. Health is described by the World Health Organization (WHO), in a widely accepted definition, as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (1946, p. 100). This description highlights how health is about the presence of attributes and abilities (a positive concept) and that the absence of ill health does not itself indicate the presence of health (McConkey, 2006).

Sen (1999) describes health as an enabling condition, and Canada's population health definition has adopted this view. It describes health as "a capacity or resource for
everyday living, that enables us to pursue our goals, acquire skills and education, grow and satisfy our aspirations" (Public Health Agency of Canada, 2004, para. 2). This broader notion takes into consideration the range of social, economic and physical, and environmental factors or determinants that contribute to health (Public Health Agency of Canada, 2004). Frankish, Green, Ratner, Olsen and Larsen (1996) similarly describe health as "the capacity of people to adapt to, respond to, and control life's challenges and changes" (cited in Young & Nicol, 2007, p. 218). Anand (2004) describes health as a "special good" and provides two principal reasons for regarding it as such: (1) Health is fundamental to a person's well being; and (2) health enables a person to "function as an agent - that is to pursue the various goals and projects in life that she has reason to value" (p.18). Therefore, according to Anand, inequalities in health are recognized as inequalities in people's capability to function.

Health, Agency and Self-Determination

The WHO Commission on the Social Determinants of Health points to the bi-directional relationship of agency and health, and proposes that "health enables agency, but greater agency and freedom also yield better health" (Commission on the Social Determinants of Health, 2005, p. 7). Agency or enacted self-determination, in turn, refers to people having the skills, opportunities and supports to act as causal agents in their lives (Shogren, Wehmeyer, Reese, & O'Hara, 2006). Efforts to promote self-determination, therefore, have the potential to both directly and indirectly affect health (Shogren et al., 2006). On a physiological level, we have learned that having greater autonomy and control (i.e., a greater sense of self-determination) over our environment and the challenges we face (i.e., our social and individual determinants) are connected to the functioning of the
immune and endocrine systems, which, in turn, affect our body's ability to deal with disease. On a psychosocial level, self-determination has the potential to enable people with disabilities to manage their own health and health care, and consequently achieve better health outcomes (Shogren et al., 2006).

International policy initiatives are recognizing the importance of this position as it relates to people with ID (Beange et al., 1999; Department of Health, 2001; U.S. Public Health Service, 2002; Sullivan et al., 2006). In parallel with the larger movement within the field of intellectual disability, efforts are being made to consider self-determination as an integral component to give people with ID greater control and choice in their own health care (Shogren et al., 2006). The International Association for the Scientific Study of Intellectual Disabilities (IASSID) Health Issues Special Interest Group recently put forth a report on reducing health disparities for people with ID. The report includes the following recommendations:

All processes to reduce health disparity should include a focus on promoting and enhancing individual education and choice over health care and health-related decisions. This includes supports that enable people to be more effective in this regard and participate more fully in such activities, and the promotion of individual self-determination.

People with intellectual disabilities are capable of assuming greater control over their lives, and they deserve the opportunity to do so and to be supported in doing so as fully and effectively as possible (Solar & Irwin, 2005). By recognizing this potential, greater focus can be placed on finding ways to encourage and support people with ID to play an
increasingly active role in their health and health care, rather than the passive patient role they played in days past (Lennox & Edwards, 2001; Shogren et al., 2006).

Health and Intellectual Disability: Mutually Exclusive?

Historically, various kinds of disabilities, including intellectual disabilities, have been equated with health problems (Lennox and Edwards, 2001). In other words, a person with a disability was seen as being unhealthy or sick. Disability, seen as equal to illness, was viewed "with similar expectations of dependence, inactivity, and exclusion from participation in community life that are typically associated with illness" (Krahn et al., 2003, p. 79). "The 'victims' were 'confined by' or 'suffering from' their conditions" (Kearney, 2003, p. 163). Tighe (2001) eloquently states that "persons with physical or mental impairments are often granted a permanent visa to the kingdom of the sick" (p.511).

The separation of health from disability is a relatively new concept (Krahn et al., 2006) and it is still developing. Sutherland, Couch and Iacono (2002) suggest that because disability is often equated with ill health, much of the research that has been done in regards to the health of individuals with ID has focused on possible consequences of having a particular disability, such as an increased prevalence of certain conditions. They stress however that “to understand health as a complex and dynamic construct it is important to take account of many factors, including potential determinants that may reduce or enhance health, as well as the processes and features of disease” (Sutherland, Couch & Iacono, 2002, p. 423).
In the following section, a further examination of the potential determinants described above is provided. These determinants are described in terms of how they fit into a model of health disparity and health inequity which guides the following exploration of the literature.

**Health Determinants**

Health determinants, a term first used by McKeown (1979), include a range of individual and collective factors and conditions and their interactions, which have been known to influence health status (Public Health Agency of Canada, 2004). According to Sowney and Barr (2003), "they are interrelated factors that contribute to an individual's ability to maintain and improve health" (p.248). Different models and conceptual frameworks separate and classify health determinants in different ways. Dahlgren and Whitehead (1991) often cited rainbow model shows the levels of causal conditions that contribute to health and differences in health between populations (Figure 1.)

![Figure 1 Dahlgren and Whitehead's rainbow model of Health (1991)](image)

This rainbow model illustrates that age, sex and genetic make-up influence people's health potential and these are considered fixed. Other factors in the surrounding
layers of the model can potentially be modified. Individual lifestyle factors such as smoking habits, diet and physical activity can potentially promote or damage health. Interactions with friends, family and mutual support within a community can sustain people's health. Wider influences on health include living and working conditions, food supplies, access to essential goods and services, and the overall economic, cultural and environmental conditions prevalent in society as a whole.

The Public Health Agency of Canada (2001) lists twelve determinants of health: Income and Social Status, Social Support Networks, Education, Employment/Working Conditions, Social Environments, Physical Environments, Personal Health Practices and Coping Skills, Healthy Child Development, Biology and Genetic Endowment, Health Services, Gender and Culture (para 3). McGinnis, Williams-Russo and Knickman (2002) grouped determinants differently and into just five categories: genetic predispositions, environmental conditions, social circumstances, behavioural patterns and medical care access. In their review of the influence that each variant has on health using early mortality as an indicator, they estimated that, for the general population, medical care is estimated to contribute about 10% and individual behaviour 40%. The other determinants were estimated as 30% for genetics, 15% for social circumstance and 5% for environment. Drum, Krahn and Horner-Johnson (2004) suggest that these figures are likely different, with health care access and environment playing a larger role for people with ID.

The Dahlgren and Whitehead model (1991), McGinnis, Williams-Russo and Knickman's investigation and the Public Health Agency of Canada determinants of health differ in the way they have classified determinants. However they provide an
overview of the complex set of factors that can influence the health of all individuals; and, as with all individuals, the health of people with ID is influenced by their unique set of circumstances and the presence of positively and negatively influencing determinants therein. Kerr (2004) suggests that "high levels of obesity and underweight, low employment, fewer social connections and meaningful relationships" (p. 201) are negative determinants that stand out in particular within the population of people with ID.

While the focus of this review centers on the determinants of access to health care, and in particular health care communication, it is important to realize that it is only one of several interrelated determinants as the afore-mentioned models suggest. In fact, models of social determinants of health were originally created to shift the emphasis onto broader nonclinical socioeconomic factors that influence health and to downplay the influence of health and medical care on the health of individuals and populations (Graham, 2004).

In the research on determinants of health, a case was made for "'refocusing upstream' to the social pattern and structures that shape people's chances to be healthy" (Commission on the Social Determinants of Health, 2005, p. 5). Nonetheless, inquiries into inequalities in health continue to highlight access to health care as an important determinant of health (Sowney & Barr, 2003) and, as Drum et al. (2005) suggest, this is even more true for people who have ID. The reasons for this will become increasingly evident in this exploration of the literature. In discussing quality of and access to health care for people with ID Graham (2005) concurs and suggests that this will continue:

Maintaining equity in care will become more important as the effectiveness of interventions – preventative, therapeutic and rehabilitative – increases and the
care system, in consequence, becomes a more significant determinant of health. Its health-determining role may be greater still for children and adults with intellectual disabilities who experience both complex health problems and multiple social and economic vulnerabilities. (p. 106)

Health Disparities and Inequities

There are discrepancies in the research literature concerning how the terms health disparities, health inequalities and health inequities are used. Different writers have different interpretations of the concepts and the resulting inconsistencies can be cause for confusion. This warrants some clarification of how the terms were applied within the conceptual framework which guided this review of the literature.

Differences in health that are seen among different populations are labeled as health disparities. The word disparity refers to a difference or inequality (Ouellette-Kuntz, 2005), and, in fact, much of the literature from Europe uses the term health inequality rather than disparity. Whitehead (1992), in the widely cited paper on the concepts and principles of equity in health, sets forth guidelines which have largely framed how inequalities/disparities and inequities are defined. Whitehead describes health inequality as "measurable differences in health experience and health outcomes between different population groups" (1992, p. 430). Whitehead further defines health inequity as "differences in opportunity for different population groups which result in unequal life chances, access to health services, nutritious food, adequate housing, etc. These differences may be measurable; they are also judged to be unfair and unjust" (Whitehead 1992, p. 430). Whitehead has provided a framework within which to
consider whether differences are avoidable and unfair based on seven determinants of health differences:

1. Natural, biological variation

2. Health-damaging behaviour if freely chosen, such as participation in certain sports and pastimes

3. The transient health advantage of one group over another when that group is first to adopt a health promoting behaviour (as long as other groups have the means to catch up fairly soon)

4. Health damaging behaviour where the degree of choice of lifestyles is severely restricted

5. Exposure to unhealthy, stressful living and working conditions

6. Inadequate access to essential health and other public services

7. Natural selection or health related social mobility involving the tendency for sick people to move down the social scale (Whitehead, 1992, p. 432).

According to Whitehead, it is the last four determinants that are indicative of health inequities and are therefore indicators of unfairness and injustice. Gatrell (2002) expands Whitehead’s definition and describes health inequities as "differentials in health outcomes which are avoidable and should be capable of being narrowed; their existence in a sense is unethical" (p. 91). Changing the negative to the positive then defines health equity as "the absence of unfair and avoidable or remedial differences in health among population groups" (Solar & Irwin, 2005, p. 6). This definition reflects the fact that, like social justice, "health equity is most often
perceived through its absence” (Solar & Irwin, 2005, p. 5) and that not all disparities are unfair. Braveman and Grunskin (2003) explain:

For example, we expect young adults to be healthier than the elderly population. Female newborns tend to have lower birth weights on average than male newborns. Men have prostate problems, women do not. It would be difficult however, to argue that any of these health inequalities is unfair. (p. 255)

The equity principle does not mean that everyone is required to have the same level of health, but it demands a distribution of determinants of health, to the extent they can be controlled, that all people have the same possibility of leading a long and healthy life (Stronks & Gunning-Schepers, 1993).

Further, confusion has persisted within the literature with regard to terminology surrounding what equity/inequity describes. The terms equity or inequity can be used to describe a cause or a difference in opportunity to be healthy. We could therefore speak of inequitable determinants. Equity/inequity can also describe as an outcome the result of a difference in the opportunity to be healthy. In this view, inequity is a subgroup within health inequalities. The debate as to whether an inequity can exist prior to, or without inequality is an interesting and complex issue that could be explored at length; however, only a brief synopsis is provided here.

Asada (2005) provided a functional schematic explanation based on Whitehead's descriptors that illustrates the school of thought that suggests that inequity can exist without resulting inequality. This assumption is made clear in a visual way in Figure 2.
Figure 2 Asada's representation of terminology of health distribution (2005)

In this illustration, Asada defines health inequalities that are caused by certain inequitable determinants as inequitable health outcomes. He also suggests that there can be inequitable health determinants that may not cause measurable health inequalities. Nevertheless, health inequities imply an "ethical or moral dimension" (Asada, 2005, p. 701).

Taken in combination, the determinants that influence health (for this purpose, the determinants outlined by Canada's Public Health Agency), Whitehead's descriptive criteria, and a modified version of Asada's (2006) illustrative clarification provide a map that can guide our understanding of the unique challenges that are faced by people with ID in striving for health. This map is illustrated in Figure 3.
As discussed above, health is the result of the effects of a number of different determinants and their complex interplay. If health between different populations is the same, we would describe it as equal (health equality). If there is a difference, we would define it as unequal or indicate that there is an inequality or disparity between populations. As Asada (2005) points out, strict equality for all is not an ideal situation as it would deny personal choice as in the case of diet, exercise and whether or not to smoke, for example, and would neglect the fact that there are some determinants that are beyond all human control. Health determinants that are "due to reasons beyond individual control" (Whitehead, 1992, p. 430) but are "amendable to human
interventions” (Anand, 2006, p. 286) and therefore can be defined as “avoidable, unfair and unjust” (Whitehead, 1992, p. 430) are inequitable.

We know that as a group, people with ID have poorer health than the general population. There is evidence to show health disparities/inequalities across a range of health areas, including physical health, mental health, sensory impairment, and oral health. Krahn, Hammond and Turner (2006) provide a simple but helpful visual representation of determinants of health and health status disparities between people with ID and the general population (Figure 4).

![Diagram showing determinants of health status disparities for persons with ID](image)

**Figure 4** Krahn, Hammond and Turner’s representation of determinants of health status disparities for persons with ID (2006, p. 72)

Making the determination as to whether these differences are attributable to factors that are amendable to human intervention is an important question that requires further research. Ouellette-Kuntz (2005), who has done an in-depth analysis of the current research in the area of health disparities of people with ID, asked this very question and provides a reflection on why the answer is simple:

Are the health disparities (described in current research) inequitable? Whitehead’s conception of inequity prompts us to ask ‘Are the differences avoidable and unjust?’ Much of the research upon which the disparities are identified failed to adequately consider this important question although a number of authors have
commented on their findings by raising issues of equity/distributive justice both in terms of discriminatory practices and social disadvantage. (p.116)

While she cautions that more research is needed to link specific determinants with the key health differences, she points out that the need to do so is being recognized increasingly. Pearcy and Keppel (2004) have also pointed out that distinguishing inequities from inequalities is not an easy task. They emphasize that incomplete knowledge should not equal inaction. These perspectives provide important considerations to keep in mind when analyzing health indicators and the determinants that influence the health of people with ID.

Health Indicators

The health problems prevalent in people with ID have been examined from a variety of perspectives. However, there is a relatively small number of studies that have included a control group of people without ID (Jansen, Krol, Groothoff, & Post, 2004). Most of the comparative studies found reported prevalence rates of general health surveys. Two such examples are offered here.

In the Netherlands, a comparative study of 318 people with ID within a general practice found that people with learning disabilities had 2.5 times the frequency of health problems of those without ID. The authors defined health problems as "anything that has required, does require or may require health care management and has affected or could significantly affect a person’s physical or emotional well being" ((Van Schrojenstein Lantaman-De Valk,2000, p. 326).

Closer to home, Balogh, Hunter and Ouellette-Kuntz (2005) carried out a retrospective analysis of hospitalization data for persons with ID living in Ontario
between 1995 and 2001. They found that, compared to the general population, hospitalization rates for mental disorders and dental diseases was substantially higher for people with ID. Of all hospital admissions, one third were for mental disorders such as schizophrenia and depression. Of all day surgery admissions, almost 40% were for dental procedures. In comparison, major in-hospital surgical procedure rates were lower than those of the general population. The authors questioned whether the discrepancies they noted were because of the prevalence of specific comorbid conditions experienced by people with ID (a biological determinant) or if a more disturbing explanation would be that a significant number of people with ID in Ontario are not receiving adequate health care (a health care access determinant). Research into mortality and morbidity gives us insight into how the health needs of people with ID differ from those of the general population.

**Mortality**

Life expectancy of people with ID has increased in a parallel fashion to that of the general population over the last three decades (Barr, Gilgunn, Kale, & Moore, 1999). This is seen most dramatically in individuals with Down syndrome where the mean age of death increased from 25 years in 1983 to 49 years in 1997 (Yang et al. 2002). Despite this positive trend, people with ID still tend to have reduced life expectancy in comparison with the general population.

The most common causes of death of people with ID also differ from those of the general population. Within the general population, the leading cause of death is cancer, followed by ischemic heart disease, then cerebrovascular disease or stroke. For people with ID, respiratory disease followed by cardiovascular disease (related to congenital
heart disease) are the leading causes of death, with cancer ranked lower. Their patterns of cancers are also different, with lower rates of lung, prostate and urinary tract cancers and higher rates of esophageal, stomach, gallbladder cancer and leukemia (NHS, 2004). Predictors of premature death in people with ID include “1) Severity of intellectual disability, 2) Reduced mobility, 3) Feeding difficulties, 4) Down Syndrome, 5) Concomitant epilepsy” (Solar & Irwin, 2005, p. 47).

Morbidity studies highlight specific health needs of people with ID. Compared to the general population, there is a higher prevalence rate of both mental disorders and physical disorders in people who have ID. Not only is there a greater need, but there is also a different pattern and spectrum of needs that presents more commonly in people with ID as compared to the general population (Cooper et al., 2004).

The most common health needs encountered by people with ID are outlined briefly below. The list is based on current literature and reflects the common physical problems discussed in depth at the Toronto Colloquium on the Primary Care of Adults with Disabilities (Cameron, 2005).

**Obesity, Physical Fitness and Nutrition**

Prevalence of obesity is high among persons with ID (Beange, McElduff & Baker, 1995; Van Schrojenstein Lantaman-De Valk, 1997), and estimates range from 33 to 57 % (Rubin, Rimmer, Chicoine, Braddock & McGuire, 1998; Lewis, Lewis, Leake, King & Lindemann, 2002) or twice as high as the general population. In addition, obesity can lead to a greater risk for other medical problems. Some researchers argue that
increasing levels of moderate to vigorous physical activity among people with ID would
be the single most effective way of improving the overall health of members of this
population (Robertson, 2000).

**Sensory Impairments**

Adults with ID have a high prevalence of visual impairment (Cassidy, 2002; Janicki, 2002). Understandably, undiagnosed visual impairment can lead to significant
difficulties in daily functioning. McCulloch, Sludden, McKeon and Kerr (1996) found
that 12% of mildly disabled people, more than 40% of severely disabled and 100% of
profoundly disabled people had poor visual acuity. In a recent study, The Special
Olympics program screened large numbers of athletes with ID for vision problems and
found 40% to have ocular abnormalities, with almost 20% reporting never having had an
eye examination (Woodhouse et al., 2004).

Likewise, hearing impairment is very common among people with ID and can be
a major contributor to communication difficulties in this population. Evenhuis,
Theunissen, Denkers, Verschuure and Kemme (2001) identified hearing loss in 21% of a
residential sample of 672 people with ID. The authors stressed the need to adjust the
environment to the sensory limitations of clients and for staff training to deal with those
limitations. Sometimes, the reason for the hearing loss may be as simple as impacted
earwax. This treatable problem is frequently a concern in adults with ID (Crandell &
Roeser, 1993).

Researchers point out that sensory impairments often go undetected by care
giving staff. In a study in the UK, Kerr et al. (2003) found that caregivers assessed vision
as “perfectly normal” for 49% of their clients, although less than 1% were found to have
normal vision on a physical exam. Similarly, staff reported 74% to have normal hearing, while formal assessment indicated only 11% to have normal hearing, with 61% having mild hearing loss, 15% having moderate to severe hearing loss, and 13% having profound or severe loss.

Dental Health

Several studies have found dental disease to be far more prevalent among people with ID than it is in the general population (Beange 1995; Scott et al. 1998; Cummella, Ransford, Lyons, & Burnham, 2000). Scott et al (1998) noted that various types of dental disease were up to seven times more frequent compared to the general population. In the Sydney population study of people with ID, the most frequent medical disorder was dental disease, which occurred in 86% of the participants (Beange, 1995). In a UK study, people with ID were more likely to have missing or decayed teeth and less likely to have fillings than the general UK population (Cummella et al. 2000). Poor oral hygiene is implicated as the primary cause along with lack of preventative care (Cummella et al., 2000; Lewis et al, 2002).

Gastrointestinal Disease

Gastro-esophageal reflux disease (GERD) and dysphasia have been identified as a major cause of suffering and morbidity among people with ID (Beange et al., 1995, Bohmer et al., 1996). It is often overlooked and underestimated (Bohmer et al. 1997). Symptoms indicative of reflux are vomiting, haematemesis, rumination and depressive symptoms (Lennox & Edwards, 2001). The overall prevalence of reflux esophagitis in people with ID has been estimated at 10-15% compared to 2% in the general population.
Heliobacter pylori infections are more prevalent in populations of both children and adults with ID than in the general population. This infection can cause diseases such as peptic ulcer, gastric carcinoma, and may be associated with gastritis and esophagitis (Ouellette-Kuntz, 2005). Chronic constipation is also very common among people with ID, and can be the root of many physical and behavioural difficulties. Bohmer et al. (2002) found that constipation was randomly demonstrated in almost 70% of the population with ID. Both physical inactivity and the use of medications such as anticonvulsants and neuroleptics may cause constipation. As with GERD, symptoms are not always recognized and, if left untreated, can lead to the serious complication of bowel obstruction (Bohmer et al 2001; Jancar, 1994).

Osteoporosis

Osteoporosis has been shown to occur with high prevalence among people with ID (Center, Beange & McElduff, 1998). Risk of fractures in this population is particularly high, possibly secondary to an increased risk of falling. As well, long term use of anticonvulsants used to treat epilepsy may lead to osteoporosis and therefore raise the risk of fractures (Wagemans et al., 1998; Tohill 1997). Van Schrojenstein Lantaman-De Valk (2000) found that fractures were 3 times more frequent in people with ID than those without ID. Unfortunately, this is an asymptomatic disease and often initially presents when a person sustains a fracture.

Epilepsy

Epilepsy occurs 15 - 30 times as often in people with ID as compared with the general population (Van Schrojenstein Lantaman-De Valk, 1997) and it is often
inadequately monitored and reviewed (Beange et al., 1995). Epilepsy affects both morbidity and mortality (Forsgren, 1996). Physical trauma of seizures, possible fractures and soft tissue injury may lead to the need for hospitalization, and research has identified epilepsy as a possibly avoidable cause of sudden death in people with ID (Forsgren, 1996). Furthermore, inappropriate treatment may result in worsening of behaviour or impaired cognitive function (Forsgren, 1996).

**Thyroid Disease**

Thyroid disease is both a cause and a complication of ID but is generally quite easy to treat (Beange, Lennox, & Paramenter, 1999). It can have very subtle and hard to diagnose presentations in persons with ID. Often the only symptom is reported by a support person who observes that the person's behaviour has changed in some non-specific way (Wilson & Haire, 1992). Diagnosis can therefore be easily missed, causing significant deterioration in health, behavior and functional ability (Beange, Lennox & Paramenter, 1999).

**Polypharmacy**

Health problems secondary to medication use are significant in people with ID. Polypharmacy (the use of multiple and possibly excessive amounts of medications) and inadequate medication review are acknowledged problems within this population (Beange et al., 1995; Reiss & Aman, 1997). Polypharmacy increases the risk of drug interactions, and may lead to sedation, increased confusion, constipation, postural instability, falls, incontinence, weight gain, sex steroid deregulation, endocrinologic or metabolic effects, impairment of epilepsy management and movement disorders.
(Cameron, 2005). Many individuals do need daily medication because of the high prevalence of epilepsy, psychiatric disorders and other serious diseases. However, they may have limited ability to consent to medication or to monitor side effects of medications.

Some startling data has been collected from international studies. Kerr (2003) looked at a large sample of people with ID (most with moderate to profound ID) prior to discharge from a large institution in the UK between 1995 and 1999. Approximately one half were medicated for behavioural problems, 96% were prescribed two or more medications, and 22% were prescribed seven or more. Lewis et al. (2002) collected data on a sample of 353 adults with developmental disabilities living in community settings in Los Angeles and found that about one third received psychotropic medication (exerting an effect on the mind, emotions or behaviour) but only 24% of these had a psychiatric consultation noted in their record. Further, 36% of this group received medication without any identifiable diagnosis, and simultaneous receipt of two or more antipsychotics was not uncommon. A recent Canadian study gave similarly alarming results. Sixty adults with ID were reviewed six years following transfer from an institution to the community in Quebec City and the authors found that over 90% were receiving psychotropic medication (Radouco-Thomas et al., 2004).

Sexual Health

Women with ID are less likely than other women to receive appropriate breast screening (Havercamp, Scandline & Rother, 2004; Lewis et al., 2002). Nulliparity is a risk factor for breast cancer, and difficulty in understanding of symptoms and performing a self exam may suggest that women with ID could be considered a high risk group. In
addition, women with ID are less likely to have a cervical (pap) test because of the assumption that they are not sexually active (McCarthy 1999). Kerr's (1996) audit of medical records found that less than one in four women with ID had undergone a pap test compared to four out of five women in the general population. Perhaps as a result of these factors, cancer and other diseases tend to be diagnosed in later, less treatable stages (Cooke, 1997).

Health Care Access

While recognized as one of a number of determinants that affect health, the extent to which a person experiences access to health care has an important influence on his/her health status. Access to health care might most simply be defined as "the actual use of personal health services and everything that facilitates or impedes the use of health services" (Anderson & Davidson, 2001, p. 14). In Canada, our health care system operates under a primary health care approach, which is defined as

**essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination.** (emphasis added)

(WHO - Alma-Ata Declaration 1978, para VI)

In their examination of access to health care, Guilliford, Figueroa-Munopz and Morgan (2001) drew a distinction between having access and gaining access. The former was taken to mean that a suitable service is available and physically accessible whereas
gaining access refers to “the initiation into the process or utilizing of a service” (Guillford et al., 2001, p. 186). Five major dimensions of access were defined as:

- wider determinants of health (preexisting factors determining health and social policies affecting the health and wellbeing of the population);
- identification of need (personal recognition);
- organization of health care (physical access dimensions);
- entry access (first contact health services e.g. GPs);
- and continuing access (second and further contact health services)

(Guillford, 2001, p. 25)

Aborz, McNally, Swallow and Glendinning (2003) modified the Guillford model to specifically examine the experiences of people with ID, taking into account the chronic and complex health problems and health needs experienced by this population. As well, they examined additional needs of people with ID including help-seeking behaviour, and the crucial role played by third parties, such as family or paid carers, in access to health care for this group. Their model is illustrated in Figure 5 and describes what they refer to as an "access continuum" (2003, p. 28) with multiple stages.
Figure 5 Alborz, McNally, Swallow and Glendinning’s access to health care continuum (2003, p. 27)

The authors begin by acknowledging the influence of the wider determinants of health and suggest that health services may directly or indirectly "influence personal lifestyle choices through health education or promotion by imparting knowledge and skills on lifestyle issues" (Alborz et al., 2003, p. 28). They go on to question whether people with ID in fact do have access to health education and promotion which highlights a key question examined more closely later in this review. The model identifies the importance of "establishing a need for health care" as the impetus for accessing health care.
Within the Alborz model, once need is established, there are organizational factors that determine whether individuals have access to services. Again, the authors point out that, in contrast to the general population, third parties constitute an additional factor as they are likely to assist with calling for appointments, ensuring transportation, and facilitating communication between people with ID and health care professionals.

In describing health care, Franklin (2004) reflects on Amartya Sen's (1999) conceptualization of health as capacity and claims,

Healthcare that enhances capability can then be understood as an appropriate expression of society's respect for its members' capacity to lead lives of value. ...Similarly, health services that mitigate pain express society's compassion. And an egalitarian bias in distribution of these services becomes an expression of the equality of society's respect and of its compassion for all its members. (para 2)

The question is whether these values are expressed consistently towards all parts of the population including those who already find themselves vulnerable and at risk. The degree of access to health care experienced by people who have an intellectual disability, then, can be seen to act as a kind of barometer or litmus test of how responsive health care services are towards the people they are supposed to support (Law, 2005).
Equity in Health Care Access

As stated earlier, the principles of equity and inequity that are used to describe health outcomes can also be used directly in describing access to health care. The fact that the studies reviewed above illustrate that people with ID do not experience the same level of health due to poorer access to health care in comparison with the general population can, using Whitehead's terminology, be seen as unfair and unjust, and therefore inequitable. Mooney (2003) defined equity as "equal access to equal care for equal need" (p.72) Leeder and Dominello (2005) illustrate equity in health care access in a poignant way:

Equity, when applied to people with intellectual disability, would lead us to provide them with more resources to maintain and promote their health, because of their greater needs, than we would provide to the general population. We would spend more-than-average time explaining to them the value of not smoking, of eating well and of having their blood pressure checked. More than that, we would work affirmatively to promote their health goals. (p.98)

Using Guillford's (2001) terminology, equity in health care refers to people having equal access to an appropriate service and gaining equal access by receiving equal benefit from the service. Sowney and Barr (2004) concur and state that "equity encompasses all aspects of the service, suggesting that equity is associated not only with gaining actual entry to the service, but also with the subsequent care and treatment that may follow" (p. 253). Sowney and Barr (2004) have provided a useful summary and define attributes of equity in access to health care as
• "The opportunity to seek or gain access to a service
• The right to avail equally of the service
• A sense of fairness
• Confidence in service provider
• Within a time frame
• Being/feeling empowered"  (p.255)

They further expand on this concept by taking Walker and Avant's (1995) suggestions to aid understanding of a concept by describing the antecedents that are present prior to and the consequences that follow equity in health care as represented in Table 1.

<table>
<thead>
<tr>
<th>Antecedents</th>
<th>Defining Variables in Equity in health care</th>
<th>Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>a desire to feel healthy</td>
<td>the opportunity to gain access to a service</td>
<td>service utilized by those who need it most</td>
</tr>
<tr>
<td>a perceived unmet health need</td>
<td>the right to avail equally to the service</td>
<td>the opportunity to experience better health</td>
</tr>
<tr>
<td>a previous knowledge of who can help</td>
<td>a sense of fairness</td>
<td>patient/ client satisfaction</td>
</tr>
<tr>
<td>the ability to make comparisons or judge</td>
<td>confidence in the service provider</td>
<td>ability to make an informed decision to follow a healthier lifestyle</td>
</tr>
<tr>
<td>a feeling of trust</td>
<td>within a time frame</td>
<td>a feeling of inclusion and acceptance</td>
</tr>
<tr>
<td>a belief of being an equal citizen</td>
<td>being/ feeling empowered</td>
<td>reduction of differences in health status between those with learning disability and those with no learning disability, in relation to major diseases</td>
</tr>
</tbody>
</table>

Table 1 Sowney and Barr’s representation of equity of access: antecedents, defining variables, consequences (2004, p. 258)
This sequential overview can aid to further guide our thinking as to what needs to be in place in order for equity in health care access to become a reality for people with ID, as well as the positive benefits that will follow when it does.

It is important to consider that, at a fundamental level, access to health care is mitigated by communication of need. Within the literature reviewed, different researchers have used proxy reports (from a support worker or parent), medical records, physical examination or a combination of procedures to determine frequency of health conditions. Some researchers have suggested that proxy reporting leads to under-recognition of health problems in people with ID (Krahn et al., 2006; Sutherland, Couch, & Iacono, 2002) and have further hypothesized that inadequate recognition and reporting of clinical signs and symptoms by support staff may affect the level of untreated illness evident among people with ID (Lunsky & Reiss 1998; Wilson & Haire, 1990). Sutherland et al. (2002) suggest that “for adults reliant on others to care for and voice their health needs, inadequacies in this area may have considerable health consequences” (p.430).

Factors that Influence Equity in Health Care Access

In theory, people with ID who live in industrialized nations have equity in access to essential health services (Evenhuis, Theunhissen, Denkers, & Kemme, 2001). In practice, evidence shows that frequently this is not the case. As previously pointed out, some of the health disparities experienced by people with ID are due to associated or co-morbid conditions. Yet evidence points to the fact that many of the health disparities experienced by people with ID can be explained by turning the focus onto determinants beyond the biological and genetic ones. For the purpose of this review, focus is placed on
the determinants of health care access and the factors that influence equity in health care access being a reality for people with ID.

Negatively influencing factors, or barriers, to health care access exist on many levels and are multi-dimensional and complex (Lennox & Edwards, 2001). In the research literature, several barriers to access in health care specific to individuals with ID have been identified or commented upon and these are highlighted in Table 2.

<table>
<thead>
<tr>
<th>Systemic barriers</th>
<th>Environmental barriers</th>
<th>Health care provider barriers</th>
<th>Support person barriers</th>
<th>Person barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Lack of health care promotion</td>
<td>• Physical constraints</td>
<td>• Attitudes and stigmatization</td>
<td>• Reliance on others for access</td>
<td>• Communication difficulties between individual, health care provider and support person</td>
</tr>
<tr>
<td>• Reactive health care system</td>
<td>• Inflexible administrative procedures</td>
<td>• Lack of knowledge and training of health care professional</td>
<td></td>
<td>• Fear and anxiety</td>
</tr>
<tr>
<td>• Time constraints</td>
<td></td>
<td>• Case complexities and diagnostic overshadowing</td>
<td></td>
<td></td>
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<tr>
<td>• Lack of coordination between health care services</td>
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Table 2 Barriers to health care access identified in the literature.

The research reviewed for this summary has been drawn from different perspectives and includes individuals with ID, health care providers, family members, and support persons. While there are clear differences among these various perspectives, there are also obvious patterns that emerge when the studies are compared. Looking again at the suggested framework (Figure 6), these barriers can be added to illustrate their negative effect on the determinants of health care access.
Figure 6 Health determinants and distribution of health including factors that affect health care access.

In other words, these factors can have a negative or positive effect on equity in health care access and thus are outlined as the red octagons (Figure 7).

Figure 7 Factors influencing health care access.
The barriers that have been recognized in the literature are summarized in Appendix I and outlined in detail in the discussion that follows.

Systemic Factors

Access to health promotion

The important influence that health promotion, or a lack thereof, can have in the lives of people with ID cannot be overstated. Having available, accessible and appropriate health promotion programs directed specifically at people with ID is an extremely important determinant in their health outcomes. A full examination and discussion of its impact is beyond the scope of this review. However, it is important to recognize that health promotion occurs in many different settings and is, or should be, very much a part of direct consultations with primary health care providers. Tones (1991) breaks health promotion into three broad areas: health education, disease prevention and health surveillance. Unfortunately, in all three areas, research points to a disparity in the level of health promotion offered to people with ID. For example, efforts to reduce obesity and smoking, and to encourage healthy nutrition and exercise are much less than for the general population (Webb & Rogers, 2002). In addition, people with ID receive less by the way of routine immunizations and blood pressure checks (Beange & Durvasula, 2001)

What is gradually being recognized is that effective health promotion strategies can go a long way toward decreasing health inequities if they are offered in a way that is accessible, relevant and appropriate for people with ID. Jobling (2001) contends that many people with ID are ill-prepared for the responsibilities that are involved in
understanding the health issues and making choices that can help them to maintain their own health. She makes the suggestion that a greater understanding of health through education can have a positive impact on health choices and states: “This understanding, developed through education, can then be used to formulate attitudes and values, which subsequently form the basis upon which individuals can take responsibility and begin to self-regulate their own health behaviours” (p.313). Finding innovative ways to encourage this kind of understanding should be a primary goal in effective health promotion for people with ID.

*Reactive health care system*

Albortz et al. (2003) describe how access to health promotion and recognizing the need for access to health care are closely linked:

Barriers to appropriate and timely access to health services operate both outside and within health services. However, the fact that some difficulties are encountered prior to first contact with health services does not mean that health service providers are unable to influence them. Strategies such as health education for people with learning disabilities and their carers may positively influence decision making about access. Difficulties identifying and communicating health need on the part of people with learning disabilities may be overcome by providing proactive strategies to identify need.

(p. 22)

The barrier here can be attributed to a health care system that operates largely on a reactive rather than proactive basis. That is, it relies largely on individuals to identify and then self report a problem or illness and seek out consultation (Glasgow, 2002).
Health care services are typically geared to patients who are able to complain and to tell their health care providers what is wrong and what they think they require. This can be problematic for people with ID who may have difficulty, first of all, in recognizing the need to seek out care, and, secondly, exactly how to go about accessing it (Alborz et al., 2003).

*Time constraints*

Another barrier to effective health care is the limitation of short consultation times on history taking and diagnosis (Beange, 1996). Extra time is often needed for examinations, tests, procedures and health teaching. In addition, “because many of these patients take at least twice as long in consultation as the average patient, the more minority patients the doctor sees, the less the doctors’ income” (Beange, 1996, p.159). In their survey Dovey and Webb (2000) found that GPs requested extra time in consultations to meet the complex needs of people with ID, but were not paid for extra consultation time.

If health care providers are not adequately reimbursed for the extra time needed, a disincentive is created that can result in a reluctance to treat people with ID (Lennox & Kerr 1997). Reimbursement systems, as they currently stand, do not necessarily encourage treating the whole person. While booking double length appointments has been suggested as a possible way to tackle barriers imposed by time constraints, the effectiveness of doing so has not yet been investigated and researched (Alborz et al., 2003).
Lack of coordination and collaboration between health care services

Bond et al. (1997) argue that health care professionals have held to the opinion that people with ID resident in the community require specialist health care services. This can result in individuals with ID falling between two health care systems and receiving neither (Bond, 1997). At times, health care professionals involved in the care of the same person may work in parallel with each other and be unaware of each other’s involvement (Lennox & Edwards, 2001). At other times, if a person is treated by more than one health care professional, for example a GP and a specialist, both may view the other as taking responsibility for the management of care described as a “diffusion of responsibility” (Horowitz, Kerkler, Owens & Zigler, 2001, p. 149). In both cases, the lack of collaboration and coordination of care can have serious negative health implications for the person with ID (Smeenk , van Haastregt, Gubbels, Witte, and Crebolder, 1998).

Environmental Factors

Physical constraints

People with mobility and sensory problems can find it a challenge to access buildings and treatment rooms. More specifically, people with ID may experience difficulties with physical examination and diagnostic interventions because of their individual physical conditions and abilities. These include what may be regarded as simple screening procedures such as weight measurement, blood tests and visual and auditory examinations (Barr, Gilgunn, Kane & Moore, 1999). In addition, reading signs and written instructions can create difficulties for people who may have low literacy skills.
Health Care Provider Factors

Attitudes and stigmatization

There is a wealth of literature that seeks to theorize about the relationships among beliefs, attitudes, and caring or professional behaviour. Many of the studies in this review have sought to investigate attitudes and/or views of support staff and health care providers working with people with ID using a number of instruments and scales (e.g. Kerr et al., 1996; Bond et al., 1997; Stein, 2000; Gill et al., 2002; Ouellette-Kunts, Burge, Henry, Bradley & Leicher, 2003).

Research has indicated that entrenched stereotypical beliefs and negative attitudes toward people with ID by health care providers still exist (Newall, 1999; Slevin and Sines 1996). As Lennox and Edwards (2001) astutely point out, "barriers that exist in people's minds are notoriously difficult to remove" (p.35). Such negative attitudes can often result in a "hands off approach" to patients with intellectual disability (Davis, Iacono, Humphreys & Chandler, 2002, p. 274) and greater reluctance to provide care and treatment because they are perceived to be "more difficult to manage" (Gill, Stenfert-Kroese & Rose, 2002, p. 1446). Furthermore, inaccurate assumptions may be made about health related behaviours. For example, health care providers may believe that people with ID do not smoke, drink, experience stress or have sexual relationships (Bond et al, 1997). "Attitudes or beliefs may influence treatment choices, the effort or associated energy that empowers or drives a health intervention, and finally how much confidence that the health care provider displays or draws upon in their particular course of action or inaction" (Lennox & Edwards, 2001, p. 36). This in turn can have the affect of lowering expectations of people with ID and their support persons on the type of
treatment, support and service they can expect (Law, 2005). As Marks and Heller (2003) point out, "changing the attitudes of health care providers is paramount in ensuring that their services enable and empower individuals to have control over their health" (p. 210).

**Knowledge and training**

A lack of knowledge and training for health care providers creates huge obstacles to health care for this population. There are essentially two strands of research that support this notion. One consists of recent studies that have reported health care providers' own perceptions that they lack adequate training to treat individuals with ID and that they feel the need for improved education for students in health care and continuing education opportunities for practicing professionals. Two such examples are those of Miller, Chorlton and Lennox (2004) and Melville et al. (2005). Melville et al. (2005) designed a questionnaire aimed at practice nurses in Glasgow to measure their attitudes, knowledge, training needs and self-efficacy in their work with people with ID. A knowledge gap regarding the health needs of people with ID was identified. Communicating with people with ID was at the top of the list of practice nurses' choice of topics for future training. Miller, Chorlton and Lennox (2004) used mailed questionnaires sent to GPs. The barrier nominated by the highest percentage of respondents (93%) pertained to further education and training. Communication training was next at 83%.

The other strand of research relates to the perspectives of individuals with ID, their families and support staff. One such example is Reichard and Turnbull (2004) who collected reports from physicians as well as service providers and family members. Their findings showed interesting results in that only a small number of families (17%) but a
much larger number of case managers (41%) rated physicians' knowledge of individuals with ID as being "poor" or "very poor."

**Diagnostic overshadowing**

The term "diagnostic overshadowing" was first coined by Reiss, Levitan, and Szysko (1982). It refers to a situation wherein the existence of the intellectual disability is said to explain the existence of other unrelated problems (Lennox & Edwards, 2001). Holland (2000) described it as "dismissing changes in behaviour, personality or ability that would be taken very seriously in a person without a learning disability" (p. 28) For example, frustrations due to difficulties in expressing distress or discomfort may result in what the health care provider sees as maladaptive behaviour. Therefore, symptoms related to physical problems may be misinterpreted as behaviours typically associated with a diagnosis of ID (Ouellette-Kuntz et al., 2005).

**Communication Factors**

In the literature reviewed, communication challenges were consistently mentioned as a significant barrier in health care access for individuals with ID (Lennox et al., 2004; Ziviani et al., 2004). Communication with those around us shapes our everyday experiences and, if we are confident in our abilities, is something to which we may not give much thought (Johnson, 2001). Johnson further states that "communication is something we take for granted when we can do it, and something we make assumptions about in others who cannot" (Johnson, 2001, p. 2).

In recent years, there has been a steady flow of literature that seeks to gain insight into the experiences of people in communication exchanges with health care providers. It
has been suggested that certain skills are needed to achieve the reciprocity of successful communication between health care providers and those in their care. While this interaction is often a challenging task for anyone, it can be especially so for people with ID. If communication between the health care provider and the individual is effective, it encourages mutual understanding, adequate diagnosis, and appropriate treatment - all essential components required to bring about positive health outcomes. Conversely, a breakdown in communication hinders mutual understanding, makes diagnosis and treatment difficult and results in poorer health outcomes (Johnson, 2001).

**Authentic Conversation**

Theorists and researchers from a number of disciplines have suggested models of interaction between health care providers and those in their care. Arnason (1994) suggests a cooperation model which takes communication as its starting point. It is based on the premise that the “objectives of health care can best be realized in conversations between patients and professionals” (p. 235). Conversation, according to Gadamer (cited in Aranson, 1994) “opens up treatment and accompanies healing” (p. 236) and is also the best way to ensure both parties (the health care provider and the individual) are treated as persons (Arnason, 1994). He further points out the tension that often exists within ethical dilemmas in health care, “where professionals must find a fitting balance between non-interfering distance and caring presence... The vehicle of that praxis is authentic conversation” (p. 236).

**Monologue, Dialogue and ... Trialogue?**
Van der Gaag (1998) states that "understanding communication as a two-way process, in which both partners have responsibility to make each communicative exchange successful, is a crucial part of breaking the cycle of negativity which colours many communicative experiences for individuals with ID" (p.9). The recognition of communication as an active process where interaction, as opposed to one way transmission takes place is essential. Barbour (2000) referred to this as the Frisbee as opposed to the shot put approach. That is, a shot put travels one way; a Frisbee is meant to come back and similarly, communication is not complete until it is received and returned. Kurtz (2002) presents this as one of the primary principles of doctor-patient communication and states:

Just giving information, (whether it comes from the physician or the patient) or telling someone what to do without feedback and other opportunities for the give and take of questions and responses, clarification etc., hinders accuracy, efficiency and relationship building. (p.S27)

In simple terms, monologic communication, or a one way transmission, involves control and manipulation in a way that objectifies the other. Thomlinson (1999), using Bubers' (1958) terminology describes it as the "embodiment of an I-It relationship" (Thomlinson, 1999, para. 4). Dialogic communication, on the other hand, suggests a two way exchange of information based on an "I-Thou" relationship where one respects the otherness of the other (Buber, 1958) and there is a genuine concern for the other instead of seeing the other as a means to an end (Thomlinson, 1999). Lee and Garvin (2003) suggest using the concept of dialogue, and information exchange is a powerful first step in redirecting current health communication relationships.
The triad of the person with ID, the support person and the health care provider creates unique challenges for effective communication, and the term triologue has been adopted by some as a way to describe the uniqueness of a three-perspectived encounter in health care situations (Platt & Gordon, 2003). The previous studies that have examined communicative exchanges among individuals with ID, health care practitioners, and/or support persons are briefly summarized in Appendix B. What follows is a discussion that highlights the unique challenges and opportunities that each participant in the triologue contribute to the exchange and how the relationship among the three ultimately contributes to, or detracts from successful communication.

*Individual Communication Factors*

As outlined earlier, people with ID face unique health challenges that often go unnoticed and therefore untreated. Beange (1996) makes a strong statement and points out that their health needs may not be recognized "because these patients are used to suffering and cannot articulate their symptoms and thus seldom complain" (p.160). It is important to realize that the great majority of obstacles to good health communication do not reside within the person with ID. Fixing the communication problem does not mean 'fixing the person' - a commonly held belief that must be challenged. However, attributing all reasons for communication breakdown to factors outside the individual is also wrong as the very nature of the intellectual disability may contribute (Lennox & Edwards, 2001).

In their model of health care access, Albortz et al. (2003) assert that identifying a need is an important prerequisite to being able to access health care. The authors point
out that having an intellectual disability can hinder the ability to recognize and interpret signals from the body and this can create the very first barrier in accessing health care. In their survey, the paid support persons interviewed speculated that people with ID sometimes do not bring health problems to their attention because they may be afraid of the consequences. Whether it is from previous unpleasant experiences or due to unfamiliarity with physical examination and screening procedures, confusion, fear and anxiety can be tremendously inhibiting (Law et al., 2005). Fear can be identified both as fear of specific procedures (i.e., pelvic exams and Pap smears) (Broughton & Thomson, 2000) and general fear of seeing a provider for care (Lennox, Dignennes & Ugoni, 1997). These feelings can manifest themselves in difficulty in cooperating with examinations and procedures and they can further complicate an examination (Evenhuis et al. 2000).

Reflecting back on Sowney and Barr's (2004) descriptors, it is therefore imperative to recognize the communication difficulties experienced by people with ID both at the antecedent or pre-service level as well as within a health care consultation. The individual has to feel confident first in communicating her/his needs to her/his support person and then to the health care provider. The communication skills of people with ID cannot be described with a general brushstroke because they vary tremendously. Difficulties may include problems with expression - intelligibility, fluency and rate of speech, and the ability to use language to clarify, negotiate, and express needs, choices and decisions; as well as understanding - recalling and comprehending spoken and/or written language (Van der Gaag, 1998; Byng, Farrelly, Fitzgerald, Parr & Ross, 2003). These difficulties can occur to varying degrees depending upon the type and extent of intellectual disability and depending on the presence of any associated physical
disabilities, such as cleft palate, cerebral palsy or hearing impairment (Van der Gaag, 1998). Memory may also play a role and Jansen (2004) describes "inadequate anamnesis" (p. 94), or the recollection of one's health or medical history, as an additional factor contributing to insufficient health care communication for people with ID.

As stated earlier, it is important to realize that fixing a communication difficulty does not imply a need to fix the person as the medical model of disability implies. Law et al. (2005) state that, within such a false view, "disability is seen as a static or fixed property attributed to the individual" (p. 171). They go on to state:

The disabling communication experiences that are frequently encountered by people with communication difficulty beg the question of where the problem is located: Is it simply my communication problem and therefore my responsibility for repair? As this focus on the individual is challenged so the fundamental question also changes; Is communication breakdown a consequence of a social event that is insensitive to the way in which I communicate? (Law, 2005, p. 171)

These questions provide important perspectives for thought and consideration. Health needs of individuals with ID often present with different signs and symptoms than those of the general population. Law (2005) further suggests that the complex nature of the unique presenting symptomatology together with the impact of the communication difficulty make at-risk populations, including those with ID, particularly vulnerable to the type of "secondary complexities" described by Heyman, Swain and Gillman (2004, p. 357).
Support person communication factors

Because people with ID experience an increased risk and rate of medical problems but greater difficulty in communicating their needs, it is often the support person who takes on the essential role of ensuring that the health status of a person with an intellectual disability is the best it can be. Researchers and health care providers alike are just beginning to recognize the unique role of the support person in health care encounters and the importance of striking a balance between supporting the person and promoting independence. While this role may be taken on by a family member or paid care provider, the focus of this review is on the perspective of the paid support person in supporting people with ID. As is evidenced, it is not an easy role to negotiate. It requires sensitivity and flexibility in terms of the amount and type of support and assistance that is needed (Beange, 1996).

To start, a support person has to suspect or be in agreement that there is a need to seek out care. He/she has to be watchful and observant of subtle changes in behaviour that may indicate a health need. If it is verbally expressed, the support person has to be in agreement with the individual that it is necessary to seek out care. In each of these cases, the support person's knowledge, both of the general condition and of the usual health and behaviour of the individual, is critical. Individual perceptions of the support person can be said to directly affect the recognition of the need to access health care and the decision to act on that need. As Alborz (2004) points out, when and if health care is accessed may be dependent on the point at which the support person "considers that a sign or symptom is a significance and needs monitoring, requires action to alleviate distress, or requires health advice from a professional" (p. 121).
Clearly, the decisions of support persons are crucial in seeking timely and appropriate health services for people with ID, and hence continuity is essential. The support person has to know the person well, which may be made more difficult due to staffing levels and turnovers. Furthermore, they have to call to make an appointment, ensure transportation is available and then often be present and act as a mediator between the person with ID and the health care provider. Within a health care consultation, the support person needs to balance the responsibility of supporting and encouraging the direct communication between the health care provider and the individual, and ensuring that the information needed to make the necessary diagnosis is made clear. In other words, support persons can play an instrumental role in ensuring that the health care provider focuses on the individual rather than on them and, in such instances, can assist the health care provider by advising effective ways of asking and explaining. Law et al. (2005) suggest that the complexities within this exchange are easily overlooked. The support person has to follow the health care provider’s narrative and know if and when to intervene with additional information. As Law et al. state “this process of developing shared meaning highlights the truly social nature of the communication difficulty” (p. 175).

Health care provider communication factors

"If you treat everybody the same, as a health care provider, you are discriminating, in favor of people who are the most like you, with whom you can communicate with the least difficulty” (Cervantes - personal communication, Jan 15, 2007). As stated earlier, people with ID can be denied the opportunity to articulate their symptoms when barriers are put in their way by the knowledge levels, attitudes and
assumptions held by health care professionals (Lennox & Diggens, 1999) and also in the manner in which health care professionals communicate (Murphy, 2006). In their interviews, Law et al. (2005) found that the communication style of the health care provider made a large difference in the confidence experienced by the individual and this, in turn, affected the amount of information that they wanted to share with the health care provider.

When individuals are faced with health care consultations that they feel are stressful or unsatisfactory they lower their expectations and feel generally disaffected (Murphy, 2006). Murphy further suggests that getting to know the patient with ID through consistent interaction is the best way to notice and evaluate changes that may indicate a health problem. There may be nonverbal clues such as changes in demeanor or behaviour that someone unfamiliar with the individual may be less likely to pick up. Thus, consistency in health care provider is crucial. As well, active listening on the part of the health care provider ultimately affects not only the experience of the individual but also the health outcome (Hand, 1999). Health care providers need to "expand their repertoire of communication and observational skills" (Hand, 1999, p. 74) and take time to understand the individual person.

Values that Support Communication

Shogren et al. (2006) point out that the willingness of support persons and health care providers to work directly with the person with ID "as a full and equal member of the health care team" (p.108) will influence the health outcomes experienced significantly. From their study that looked at the experiences of people with aphasia and their support persons in health care communication, Law et al. (2005) drew the
conclusion that positive health care outcomes such as accurate diagnosis, appropriate treatment, expressed consumer satisfaction are not simply a result of specific behaviours or skills on the part of the health care provider, for example communication skills, but rather are attributable to underlying processes underpinned by values (Law et al., 2005).

Byng et al. (2003) support this notion and state:

The current focus on user involvement mechanisms, communication skills training, and methodologies of patient centered care need to be rooted in deliberations about underlying values, because they simply represent mechanisms for the delivery of values, not an end in themselves. Unless we prioritize ways of examining and sharing our values, attending only to the mechanisms of delivery will not make a difference to the experience of health care provision. (p. 4)

These authors suggest that values are expressed through communication not in an explicit way but rather “in the same way as practice articulates theory, communication reveals and discloses the hidden values, assumptions and inferences of writers and speakers” (D. Klassen, personal communication, Feb. 15, 2007).

Focus of the Present Study

Given the central importance of communication, both dyadic and triadic, in health care for people who have ID, the focus of the present study was on looking beyond a skills and behaviours approach to communication to exploring what participants representing the triad felt to be the necessary values that support an effective exchange. Recognizing and operationalizing these values may in turn suggest ways to help in breaking down communicative barriers to equity in health care access for people with ID.
REFLECTION

Qualitative research is often referred to as interpretive research. It is concerned with the meanings people attach to their experiences of the social world and how they make sense of that world. This study strives to listen to the multi-perspectived voices of people reflecting on their own experience as participants in health care communication, whether as an individual with an intellectual disability, a support person, or as a health care practitioner.

It is imperative to keep in perspective the motives, presuppositions and personal history of the researcher that leads towards and subsequently shapes a particular inquiry (Caelli, Ray, & Mill, 2003). Doing so encourages a critical reflection about what the driving force is behind the desire to engage in a particular field of research. My perspective as researcher is multidisciplined, firstly as a nurse, secondly as a student within the Child and Youth Studies graduate program and thirdly as someone who has gained the understanding of qualitative methods largely from teachings through the Faculty of Education. This background has brought together a blend of applied and social science philosophies that has shaped the methodological approach in this study.

An integral part of nursing practice, and embedded in Rogerian nursing theory (1992), is the thought of giving voice, or advocating for those most vulnerable in health care. Those viewed to be placed in this situation include those at both ends of the age spectrum – children and the elderly as well as those who, through communicative challenges, are faced with health care inequities, including those whose first language is other than English, those with dysarthria, and people with ID. Recognizing this form of advocacy as a fundamental imperative in any holistic nursing practice has been a guiding
principle that has shaped my approach as a practitioner, and my goal was to adhere to research methods congruent with these values.

However, I also wanted to undertake this research without the "self-aggrandizing stance" of which Thorne and Darbyshire (2005) warn and see the research process as "the hero's odyssey... battling the adversary" of, in this instance, inequitable health care for persons with ID "armed with little more than a pet philosopher, fervent-self belief and the ubiquitous power of 'my participants' voices'" (2005, p. 1110). Rather, I have sought to provide a transparent and thoughtful account of the views expressed by the research participants I interviewed and my interpretations of the themes that I saw reflected in the data.

Breuer (2000) identifies multiple characteristics that may draw researchers toward or away from particular topics of research. Included in these are the elements of intellectual and emotional comfort, individual interest in a particular phenomenon, and attraction toward certain roles that complement individual ideologies. In this instance, the health focus portion of the 3Rs: Rights, Respect and Responsibility Project created a unique opportunity that enabled me to come alongside an existing research project and undertake the present study in parallel with the health self advocacy training project.

According to McPherson and Thorne (2006),

We enter our studies from an analytic or philosophic perspective that tells us something of the nature or structure of the phenomenon we seek to explicate, and we ask research questions that reveal strong assumptions about how it will look when we actually find it. (p.5)
In choosing participants and in formulating research questions, there is already the underlying supposition that the communication that occurs in health care settings has an important influence on the lives and well-being of people with ID. My own experience, as well as an extensive literature review, produced the foundation on which the preliminary understanding of the field of inquiry was based.

**METHODOLOGY**

**Study Objective**

Effective health care communication at all levels is paramount in promoting health for individuals with ID. Health care communication, in turn, “both constitutes and reflects the process of health care” (Collins & Britten, 2006, p. 43). If communication between the health care provider and the individual is effective it encourages mutual understanding, adequate diagnosis, and appropriate treatment - all essential components required to bring about positive health outcomes. Conversely, a breakdown in communication hinders mutual understanding, makes diagnosis and treatment difficult and results in poorer health.

The results within the present study provide information to support the concurrent development of a Health Advocacy Training Program that is being undertaken by a Brock University-Community Living Welland Pelham 3Rs research team. The content of the Health Advocacy component of the 3Rs training is based on existing literature which points to communication skills of all persons involved in health intervention interactions as being integral to ensuring good health care and, in turn, good health for people with ID. The present study actively contributes to this training by using a multi-systematic...
approach to gain greater understanding of the specific issues people with ID face in health interactions and by examining specific strategies for how communication can be improved. Byng, Farrelly, Fitzgerald, Parr, and Ross, (2003) state that “service users need greater awareness of how to support themselves in health care interactions, to ensure that they get the most out of the encounter and to ensure that their communication needs are understood” (p.5).

The aim of the study was to illuminate the differences and commonalities of perspectives of the key players involved in health interactions for people with ID and thereby establish how health self-advocacy can be encouraged and supported.

Methods

Qualitative research methods are those which employ the use of naturalistic approaches for the purpose of holistically understanding human experience in context specific settings (Patton, 2002). Giacomini and Cook (2000) state that “qualitative research questions tend not to ask ‘whether’ or ‘how much’ but rather to explore ‘what,’ ‘how,’ and ‘why’” (p.478). In the present study, the first two of these descriptors can be applied to the aim of the project which sought to determine:

1) What barriers to health care access are identified by the informants in the study?
2) What key elements are needed to facilitate successful patient - health care provider communication? (skills and values)
3) How do the informants view their role, and that of the other participants, in health care communication?

And finally,

4) How do the responses differ by informant group?
The focus of qualitative research is to recognize patterns and relationships by exploring and describing social phenomena including surveying diverse perspectives or giving voice to those not usually heard (Sofaer, 1999). The resulting information can then be analyzed for themes which may point to solutions or become the basis for theories. Utilizing a research methodology which uses an interview format allows participation by people who may have limited literacy and gives a voice to people who may have been precluded from other forms of research (Ziviani et al., 2004).

Formulation of Questions

Patton (2002) states that questions in qualitative interviews should be open ended, neutral, sensitive, and clear to the interviewee. The questions for the semi-structured interview protocol for the present study were designed with these qualities in mind. The questions asked of each group of participants aimed to draw out information regarding each participant’s unique perspective and to explore individual ideas and experiences. The questions specifically examined participants’ reflections on how they view themselves and the other participants in health interactions, and what strategies they feel are essential for good health communication as well as what hinders it. The interview questions are included in Appendix C.

Sampling Method

In order to gather information that provides diverse perspectives, informants consisted of the following key groups:

5 adults who have an intellectual disability and are living in community settings
5 front line support staff working in community agencies that support people who have ID
4 health care providers who have a recognized interest and expertise in health care for people who have ID

The first group of participants included adults who have been identified as having an intellectual disability and who are living in community residential services operated by a community-based service agency in southern Ontario. The 3 men and 2 women who took part expressed their own health status as “good” or “pretty good”. The views and experiences of these participants with ID provided the essential first-person lived experience that provided the basis for the research. As Lennox and Edwards (2001) point out “Research and discussion about health status or health outcomes for people with intellectual disability has tended to imply passivity with the patient/client/consumer silently receiving something or having something ’done’ to them” (p.1).

The present study places the views and experiences of the people with ID themselves at the focus of the research. Recruitment information was presented to potential participants who have participated in the 3Rs Human Rights Training program through their agency before being interviewed for the proposed study. Agency staff forwarded recruitment information to the people they support. The fact that the participants with intellectual disability have received this training in the past provides a unique circumstance. Through this training they have actively engaged in a program designed to give people with ID the opportunity to learn about their human rights and to explore the concepts of rights, respect and responsibility (Owen et al., 2002). While the amount of time that has passed since the training may vary among participants, this
training may have influenced the narrative they provided about their experience. The possibility that their past 3Rs training may have influenced how participants chose to articulate the answers to the interview questions cannot be discounted. However, it was felt that having had the opportunity to discuss rights, respect and responsibility within a larger context possibly made the concepts discussed for the purpose of this study easier to understand and articulate and therefore contributed in a positive way.

The next group of informants were front-line support staff from the same Association for Community Living in the Niagara Region in which the 3Rs project has provided training. Potential participants were approached by another member of the 3Rs project and asked if they were interested in participating. Staff who had been working within the association for a longer time were approached as it was felt they would have more experiences to draw from. All of the staff participants had a minimum 5 years of experience working within the Association for Community Living. The staff participants comprised of 3 women and 2 men. An exploration of the views and impressions of this informant group augmented the understanding of the environment in which the people with ID are living and provided unique insight into the staff members’ perception of their role in supporting health communication and health advocacy. It is known through past research (Cheetham et al., 2007; Lennox & Edwards, 2001; Ziviani et al. 2004) that support staff members’ reactions to health needs have the strong potential to act as a bridge or as a barrier in ensuring effective health communication for the persons they serve.

The final informant group consisted of health care providers with a recognized interest in the field of intellectual disabilities. The first Canadian Consensus Guidelines
in the Primary Care of Adults with Developmental Disabili ties was published in November of 2006 (Sullivan et al., 2006). A training course has recently been launched to introduce and facilitate discussion around these guidelines and issues surrounding health care for people with ID. As one of the first trainees in this course, through our initial workshop and though participating in teleconferencing modules, I have had the privilege of getting to know a group of health care providers (doctors and nurses) who have all had experience in caring for people with ID. By taking on the completion of this course, they have also demonstrated a keen desire to expand their knowledge and understanding of the health care experience of people with ID and therefore provided a unique and important perspective from their own practices. The list of participants in the group provided prospective informants. Once again, a letter of invitation was sent followed by a personal phone call. The health care providers who took part represented a group of “thoughtful clinicians” (McPherson and Thorne, 2006, p. 9), who possessed a recognized knowledge and expertise based on both interest and experience. All of the health care provider participants were physicians who worked in either a clinic or private practice setting. Three of them were male, one was female.

The relative stability of the health of individuals with ID is dependent on a number of relationships (Law, 2004). The participants within the present study exemplified the multiple systems involved in these relationships and were chosen with this in mind. Purposeful sampling was used in order to recruit informants from whom it was believed that important lessons about communication in health care settings could be learned.
Data collection

Following a review by the Brock University Research Ethics Board, 14 participants were recruited. Individual, face to face, semi-structured interviews using open ended questions were conducted by the researcher. The interviews, which lasted approximately one hour each, were digitally recorded and fully transcribed verbatim, and were then read and listened to several times by the researcher to ensure familiarization with the data and to ensure an understanding of the fullness of the interview narratives. The locations of the interviews were decided on by the participant so as to accommodate the setting that would be most convenient and comfortable for them. For the individuals supported by the agency, this included a private room in their home or at the association. Likewise for the support staff interviewed, some preferred meeting at the group home where they worked, while others choose to meet at the association. The health care providers interviewed chose to meet at their home or at their office/clinic, depending on their schedule. All efforts were made to accommodate preferences in time and location so as to ensure that all participants felt most at ease. As well, privacy and confidentiality were strictly upheld so that all participants felt open to share their thoughts and experiences.

The process of recruiting and interviewing individuals with an intellectual disability in the semi-structured interviews was itself informative and drew the attention of the researcher to some of the communicative challenges that may be present in consultation settings. It expanded the researcher’s understanding of tailoring communication style to the individual’s needs. For example, it highlighted the
importance of allowing sufficient time, being comfortable with pauses in conversation and the importance of checking back to ensure that information is clearly understood

Data Analysis

This study incorporated a qualitative content analysis method which involves the open coding of data and the building of a set of themes to describe the phenomenon of interest (Morse and Field, 1995). As Graneheim and Lundman (2003) point out, qualitative content analysis and interpretation involves a thoughtful balancing act. “On the one hand, it is impossible and undesirable for the researcher not to add a particular perspective to the phenomena under study. On the other hand, the researcher must let the text talk and not impute meaning that is not there” (p.111). Thorne points out that despite a careful adherence to open participation and collaboration by the interviewees, it is ultimately the researcher who makes the final decision on “what constitutes data, which data arise to relevance, how the final conceptualizations portraying those data will be structured, and what vehicles will be used to disseminate the findings” (Thorne et al, 2004, p. 12). It is therefore imperative that the means which led to the end, or the way in which the data were analyzed be presented in a transparent way. Accordingly, a thorough description of the analysis follows.

NVivo Qualitative software was used to assist in the task of sorting and coding the data and involved looking for patterns that emerged both between participants and between participant groups. This proved to be a very useful tool in gathering meaning units of data, establishing links, and organizing and reorganizing the data. A systematic process that followed the prescribed standards of qualitative research was carefully adhered to in an effort to examine both the manifest and latent content of the data.
According to Downe-Wamboldt (1992) and Kondracki et al. (2002) analysis of what the text says deals with the content aspect and describes the visible, obvious components that are referred to as the manifest content. In contrast, analysis of what the text talks about deals with the relationship aspect and involves an interpretation of the underlying meaning of the text, referred to as the latent content (Downe-Wamboldt, 1992; Kondracki et al., 2002). This study set out to provide a careful examination of both these layers of data.

Each of the three participant groups was initially coded separately. Each of the interview texts was sorted into 5 content areas which were drawn from careful review of the literature and served as a framework for the development of the interview questions, as well as a template for the sorting of data. These content areas were created to direct the coding process, and were inclusive, in that no text was left out, and in several instances sections of texts, such as specific incidences, were included in more than one content area. These were labeled as systemic factors, environmental factors, individual factors, support person factors and health care provider factors. Initial coding involved multiple readings of the transcripts to identify “meaning units” which refers to the “constellation of words or statements that relate to the same central meaning” (Graneheim and Lundman, 2003, p. 106). Others have referred to this as a textual unit (Krippendorff, 1980), and idea unit (Kovach, 1999) or unit of analysis (Downe-Wamboldt, 1992). I chose to follow Graneheim and Lundmans’s example of considering meaning units as “words, sentences or paragraphs containing aspects related to each other through their content and context” (2003, p. 106). The meaning units were then labeled with a code, a descriptor drawn directly from the text. The various codes were compared based on
differences and similarities and sorted into subthemes, which reflected the direct findings and manifest content within each of the participant groups. The subthemes from each participant group were then further examined and compared to look for cross-group commonalities and divergences. Reflection on the subthemes and a review of the literature related to the subthemes provided phenomena that were interpreted as relevant headings to unify and reframe the subthemes into themes. The themes reflect the latent pattern derived from the data.

Establishing Trustworthiness

Qualitative research findings should be evaluated based on the procedures used to generate findings and whether these meet the requirements of trustworthiness. Lincoln and Guba (1985) provide four criteria for establishing trustworthiness in qualitative research, and those criteria were carefully considered over the course of the study.

Credibility

Credibility deals with the focus of the research and relates to confidence in how well data and processes of analysis address the intended focus (Polit & Hungler, 1999). The first question concerning credibility must be considered when making a decision about the focus of the study, selection of context, recruitment of participants and approach to gathering data (Graneheim & Lundman, 2003). Choosing participants with different experiences and perspectives increases the possibility of shedding light on a research question from a variety of aspects (Adler & Adler, 1988; Patton, 1987). In this study, including narratives from 3 participant groups contributed to a triangulation of perspectives. The data collection strategy was designed to elicit the multiple perspectives
of individuals with ID, health care providers, and support persons. This triangulation acknowledges that different points of view, while equally valid, when considered together provide a greater understanding of the whole phenomenon under investigation. Siegel (1999), in describing triangulation, states “the best way to elicit the various and divergent constructions of reality that exists within the context of a study is to collect information about different events and relationships from different points of view” (para. 3). The multi-perspectived approach of the present study applies this important concept.

Choosing the most appropriate method of data collection is also important in establishing credibility (Graneheim & Lundman, 2003). In the present study, open ended questions began with broadly phrased perspectives and were followed by more specific probes regarding experience. Confidentiality was emphasized and closely adhered to and therefore participants were able to answer questions openly and honestly suggesting that responses to the questions reflect the way in which each participant interpreted his/her experiences in an accurate way. The accounts that the participants provided were coded and analyzed methodically and the findings that are presented are rich in representative data from the transcribed texts.

Transferability

A clear and distinct description of the context and culture, selection and characteristics of participants, data collection and process of analysis provides the reader with the opportunity to make judgments about transferability to other contexts (Graneheim & Lundman, 2003; Lincoln & Guba, 2003). The purposeful sampling method has provided a range of different perspectives, and the rich and vigorous presentation of the findings provided in this study includes detailed descriptions of the
interview narrative. However, it is also important to point out that the participants in the 3 groups cannot be presumed to represent the entirety of perspectives from all people of the groups they represent.

*Dependability and Confirmability*

The systematic analysis and interpretive description within the present study are presented in a way that offers a transparent explanation of how thematic interpretations have been made, an essential criterion for establishing trustworthiness (Barbour, 2001). The findings in this study are the clear products of the process of inquiry, and the interpretations and recommendations made here within are drawn transparently from the narrative data. It is important to acknowledge openly that all qualitative research, to some extent, is influenced by the subjective experiences of the researcher. An awareness of this was used for reflexive consideration and kept in perspective throughout the research process. Mays and Pope (2000) point out the importance of being sensitive to “the ways in which the researcher and the research process have shaped the collected data, including the role of prior assumptions and experience, which can influence even the most avowedly inductive inquiries” (p. 51). This study has aimed to enhance dependability and confirmability by presenting findings in a clear way and also by acknowledging that the discussion of latent findings represents “the most probable interpretations” (Grandeheim & Lundman, 2003, p. 110).

**FINDINGS**

The findings of each of the participant groups are presented here within one at a time. As described in the review of methods, data were sorted into content areas provided
by the extensive review of the literature which informed the questions used in the interviews. To a large extent, the barriers to health care access described by the participants echoed those described in previous studies and emphasized the ongoing need to ensure that these persistent obstacles are addressed and overcome. In the interviews with all groups there was a clear emphasis on communication as a potential barrier in influencing the health and wellbeing for people with ID. Participants were very open to sharing ways in which individuals and groups can work on improving health care communication practices. The following findings present the most significant subthemes drawn directly from the rich data provided by participants.

Perspectives of Individuals with ID

*Environmental Factors*

Two of the individuals interviewed used wheelchairs and described their experience finding that maneuvering in medical offices and clinic settings presented a challenge. They expressed frustration that the front doors of some medical buildings were not equipped with an opener button, that hallways and examining rooms were often narrow, and that examination tables were rarely adaptable to their needs.

Well, first you’ve got to get through the door. Well, I can’t get through, someone has to open it. You’ve got to go through the narrow hallways, you’ve got to fight to get into one of the rooms, you’ve got to sit there and wait for him and then you have to fight to get back out again.

*System Factors*
Getting timely appointments was seen as something that was usually easily achieved. One individual, however, said that he felt that his primary health care provider referred him to the ER much too often and, sometimes, for minor ailments that the individual felt could be handled in a clinic setting:

He sends me to the hospital all the time. That's one of his new tricks. Instead of dealing with the problem he sends me there and then I get some quack.

He speculated that the reason for doing so was because it was difficult for him to get in and out of the office, making examination a challenge for both him and for his health care professional. However, the resulting interruption in the continuity of his medical care led to frustration for him.

Individual Factors

The concern regarding expressive difficulties

One participant discussed his own frustrations with finding the right words to express his concerns and needs to his health care provider.

A (Interviewer) Do you find it easy or hard to talk to the doctor?

B (Participant) Hard

A Hard?

B A little bit hard

A Ok. What makes it hard?

B I can't find the right words.

The difficulty of finding the right words to make sure the health care provider had a full understanding of his situation made the visit challenging.
The concern regarding fear and anxiety

Several of the individuals interviewed acknowledged that fear had the potential to be a significant barrier. One individual shared an experience regarding her housemate whose fear and anxiety resulted in her refusal to undergo an invasive diagnostic procedure. This woman described how she had helped to alleviate her housemate’s fear by explaining that she knew what it was like since she had been through the same procedure and she offered to accompany her housemate to the visit:

B (Participant) We were trying to get Sarah (housemate) to do this but I guess it’s... One day she may have to be put to sleep just to do it, because that’s what they do at other group homes, they put girls to sleep to do that.

A (Interviewer) Is she anxious about it?

B She’s scared, she won’t even let Dr. Smith do it. I said would you do it if I went in there with you and Jane (staff) and she said maybe.

Health Care Practitioner Factors

All of the individuals interviewed had a primary health care professional or ‘family doctor’ with whom they were connected. Individuals described in detail actions of the health care professionals that they found to either promote or break down the possibilities of establishing good communication.

The Importance of Two-Way Conversation

Of primary importance to individuals with ID who participated in this study was the principal theme of feeling listened to and spoken to directly. At first glance, this may seem to be a straightforward concept in all communication experiences but one which
several individuals said was not always upheld in their encounters with health care professionals:

A (Interviewer)Tell me what the best doctor in the world would be like?
B (Participant)Well, the best doctor in the world would just prescribe the right medication and not just looking at me and not letting me talk...I don’t need that.
A Right, so he would prescribe the right medications and listen to what you say.
B He’d let me talk. Yeah.

Individuals expressed their frustration when they felt rushed and were denied the opportunity to express themselves. Individuals described varying experiences of being given the opportunity to express their own needs. Some said that the health care providers spoke to them directly while others found that health care professionals tended to talk to the staff member accompanying them. One individual relayed his negative experience and his subsequent frustration at being referred to in the third person by a health care professional who talked to the community staff member who accompanied him to the appointment.

A (Interviewer)And do you find that the doctor addresses those questions to you or does he address the questions to the staff or the person you brought with you?
B (Participant) Staff.
A Yeah?
B Major
A Is that right? Tell me more.
B Oh, if, if he’s saying something he’ll just look at the staff member and say, ‘so what are John’s eating habits. Or what has John drank today?’
A Is that right?

B Instead of addressing to John. ‘Hey I’m here!’

A Yeah. How do you feel about that?

B (double thumbs down)

Concern Regarding Poor Explanations

Inconsistencies in how health care providers provide explanations and use words that are difficult to understand added to communication challenges for the individuals interviewed. As one participant indicated,

A (Interviewer) Does he explain things in way that’s, that’s good?

B (Participant) Yes, sometimes. But he uses so many big words. I don’t understand.

Another individual summarized what separated a good from a bad experience in a health care encounter as “when they don’t judge me for the way I am.”

The Importance of Continuity

Individual participants emphasized strongly that continuity and having an ongoing relationship with their primary health care provider was valued highly. The most frequent frustrations over poor communication were expressed in instances when individuals met with a care provider with whom they had had no previous contact. One participant described this experience as follows: “Well, if you go in there they don’t know you very well, they talk down to you, they look down even, they tend to avoid eye contact.”

Conversely, informants who had a long standing relationship with their health care provider were more likely to express feeling comfortable and less anxious about
medical visits. Individuals said that one of the most important ways to ensure good care was that health care professionals should "try to understand me" and "to find out the way I work." Health care providers who were seen to make the effort to do this were described as "honest and straightforward", "friendly" and "caring".

*The Importance of a Welcoming Manner*

A sense of humour and a welcoming manner were also mentioned frequently as important attributes of good health care providers. For example, "Well, he’s always joking. And he is always, he always has a smile on his face when he sees me so, it’s almost like he is glad to see me when I arrive there."

*The Importance of a Knowledgeable Health Care Provider*

Several participants who shared that they have had long standing medical concerns (conditions unrelated to their intellectual disability) emphasized the importance of feeling that their health care provider was knowledgeable and well read regarding their health concern. In addition, several participants emphasized the importance of feeling that the health care provider was familiar with their background and history, and took the time to look over previous documentation to familiarize him/herself with pertinent information:

B (Participant) I feel like they don’t read enough on you.

A (Interviewer) Hmm

B When they come to see you in the hospital or whatever.

A (Interviewer) And they don’t read enough, they don’t know enough about you.

They don’t read your history?
B Right.

A Ok.

B I find if they would just take five minutes or ten minutes to sit down and read up on you that they're going to get a general idea of what they are dealing with.

The importance of prescribing the correct medication was stressed by several individuals who emphasized the importance of feeling that they had confidence that the health care provider would order the right medication, and provide a complete explanation of what results might be expected from it.

So he knows exactly what kind of pills I need and stuff. So... And he will tell me, if there's any side effects. He'll explain that to me. So I know ahead of time so, and he won't give me too much of a dosage if it is strong. Because at one time there was and it made me too sleepy and he cut me back.

One individual summed up his ideal health care practitioner in the following statement.

I would, now this is my opinion, uhm, a good doctor to me would be a good listener and understand the patients needs and wants. And umm, hopefully go from there.

*Support Person Factors*

The role that the support person plays in ensuring both access to good health care and in establishing good communication with health care providers was conveyed strongly by the individuals interviewed.

*The Importance of Continuity and Knowing*
As indicated in the section that addressed issues related to health care professionals, continuity and ongoing relationships with community support persons were seen as being extremely important in the lives of people with disabilities. One individual spoke about the ability of support persons to respond to their nonverbal cues.

A (Interviewer) Who would you talk to? If you feel, if you’re not feeling well at home?

B (Participant) Oh, they’d know right away.

A They’d know right away? Would you tell them?

B No

A They’d know without you telling them?

B Yeah.

A How do they do that?

B I don’t know.

A Ok.

B They must have been around me a lot.

*The Importance of Being Able to Choose Support*

Participants expressed differing preferences about whether they chose to meet with their health care provider alone or with a support person accompanying them. Several people indicated that this was dependent on a number of factors such as with whom they were meeting and the nature of the issues being discussed. Individuals also gave varied descriptions of how they perceived their opportunity to choose whether or not someone attended appointments with them and who that person was. One individual
emphasized that, in his experience, it was up to him whether his support person attended appointments with him:

A (Interviewer) Does she come into the examining room with you or does she wait outside in the waiting room?
B (Participant) Oh, she comes in.
A She comes in, yeah? Do you prefer that she comes in with you or do you prefer that she waits outside?
B I prefer she comes in, I let her come in too.

Others indicated that staff had always automatically come into examination rooms with them so this had become a routine that was never questioned. The majority of participants felt that the presence of the support person was, a positive factor for them.

B (Participant) And he can tell her, because sometimes I can’t umm like answer for myself some of the questions that he asks, so.

A (Interviewer) So he gets her point of view.

B Point of view. Because sometimes he does need a second person to talk to.

Informants’ experiences varied with regard to their perceived control over who attended health care appointments with them. They felt that usually it was “whoever is available” or “whoever is on [duty]” although several people said that they had a particular support person whom they preferred to have as health as supporters when they were available. Of primary importance to informants was the expectation that the support person would assist in providing information to the health care provider, in answering questions that the health care provider asked, and in providing comfort measures when needed. The specific expected and desired involvement of support persons in health care
interactions varied greatly from individual to individual. In some cases, it was expected that support would take the form of practical tasks such as transportation and documentation, while others expressed the need for support persons to “know the answers” to health care providers’ questions.

Other participants expressed their strong preference to meet with their health care providers on their own and found the presence of a support person would detract from their conversation with the health care provider because he or she would direct questions to the support person. Thoughtful consideration must follow how one interprets the remark of one of the individuals interviewed as he stated, “they try and talk for me, but I don’t mind.”

Perspectives of Support Persons

Individual Factors

The Concern Regarding Fear

Regarding individual barriers, support person participants mentioned fear as the primary factor to be overcome when accessing health care. This ranged from apprehension at seeing a specialist who was new to the individual, to anxiety about equipment such as having to wear a halter monitor, to the more severe feelings of being “terrified of medical appointments” or that any health care experience is “always traumatic.” One participant spoke on the collaborative efforts of staff and health care providers to reduce one individual’s acute fear in health care encounters:

One person, their experience is, it’s not good, it’s as pleasant as the doctors can make, the staff can make it, but they just have a fear of going.
Grew up in an institution, I don’t know what happened. I don’t know, I just know when she first came to live here, she’s only been in this home know, about maybe 4 or 5 years, she had to be sedated for each doctor’s appointment, she no longer needs to be sedated for doctor’s appointments at all. Um, we’ve got to the point where there are no sedation and no tears, we’ve got to that point, so there’s been some progress made.

Several support people mentioned the fear of needles as being a frequent concern. This may suggest that preparation for an appointment where blood work or injections are necessary should include a topical anesthetic shown to drastically reduce pain in such instances, and thereby lessening the apprehension as well (Buhse, 2006). In addition, some participants made the suggestion that while some individuals they support will communicate openly regarding how they are feeling, others will not, and may wait until symptoms are more severe before reporting them. This prompted some participants to speculate that some individuals may have a higher pain threshold than others:

“Sometimes they don’t, they have a higher pain tolerance some of them do, or they don’t really know that what they’re feeling isn’t right until it’s like really bad and then they’ll tell us.”

The Concern Regarding Expressive Difficulties

Support staff participants reported that, in some instances, feeling unwell may not be communicated directly by people who have ID because of their expressive communication difficulties, fear, or a combination of both. Several support people spoke about their concern that acquiescence and wanting to give the desired answer would
sometimes stand in the way of individuals fully disclosing their symptoms, particularly in an unfamiliar environment, such as an ER or inpatient setting.

I think, just because, some of the nurses and the doctors are really good, but it’s still people that they don’t know so sometimes the individual will tell you what they think you want to hear and it’s not getting the correct answer so they’re thinking “oh, okay you’re feeling better, we’ll send you home,” meanwhile, they’re not.

For individuals who do not use spoken words or alternative tools to communicate, the challenge to pick up on nonverbal cues and symptoms requires perceptive observation skills on the part of both support staff and health care providers. Several support staff emphasized the importance of having a thorough knowledge of the person’s history as well as the ability to “pick up on” concerns that may or may not be expressed.

So I think it’s really important that the staff is really aware of what the person has, as far as health issues in their life and know that person well enough to know that something is off, even if the person is not saying, or if they’re saying everything’s fine.

*Health Care Provider Factors*

All of the support persons who were interviewed began their discussion of contact with health care providers for the people they support with a statement indicating that things are “much better than they used to be.” One of the participants made the following observation:

I think that some of the health care has improved from what I have seen in the past. Where the individuals don’t really get a say, like it’s more, I don’t know
there is more, they talk to the people that we’re there with instead of us all the time. That kind of thing.

The Importance of Speaking and Listening Directly

The importance of speaking directly to the individual was an overarching theme in the interviews with staff. Support staff said that the recognition of that by health care providers was seen as a sure indication of a genuine attempt by the health care providers to establish good communication.

He was amazing, it was like he actually sat and talked to the individual, he didn’t talk to me. He asked them the questions and he let them answer the way that they could, even through a nod, he figured that out himself, and so it was like, wow! You don’t see that too often, you know, ‘cause before it was always they’d look at you and that person was just sitting over there collecting dust type thing, even though you’d be like, you can talk to the person, but he did and he, the care he gave them was great, it wasn’t okay, in and out, ok, get out, he made sure he went over their whole medical history, kept them longer cause he just wanted to make sure everything was okay, so it was, it was nice.

When prompted to suggest reasons for the positive changes, participants suggested that having greater contact with individuals with ID, both in and out of health care environments, had made a positive contribution to health care providers’ greater sensitivity. As well, they recognized that their own actions played an important role in this positive trend. One individual summarized both perspectives:

I think because, partly, I think it’s due to the staff going in and saying (gesturing beside him)... You’re here to see him, not me. We’re here to see, he’s here to see
you not me to see you. If you need information from me, we’ll give you the information you need to help you do your diagnosis, but you are here to see him and with, and we have found with the GPs that they have gotten a lot better, number one they see the guys a lot more, because they see them a lot more they are a lot more comfortable with the population that we support, take that a step further, they become friendlier with the population we support especially you know some of the guys that live here.

Several support persons made the suggestion that this was further reflected in the observation that it is often younger health care providers who seemed more aware of the importance of directing their initial conversation to the individual:

Some doctors are really good about it, and other doctors are very old-school I think and they’re kind of from another generation, they haven’t really caught up with the times that people can speak for themselves and they have the right to.

This difference in attitudes in relation to age may be attributable to changes in social policies (Gill, 2002). Other support persons echoed the notion that a large part of their role in health care consultations involves insuring that the conversation is redirected to the individual as necessary. This includes the use of both subtle cues such as positioning, ensuring that the individual is seated in a prominent position while the support person stands back, in some cases, making the direct suggestion. “Why don’t you ask HIM?”

The Importance of Allowing Enough Time
Taking the time to listen to an individual makes a tremendous difference in how the health care professionals’ approach is perceived both by the individuals themselves, and by their support persons.

The doctor’s like nice and personable and actually listens like sometimes these guys go off topic all the time... like, they want to tell the doctor what they did that day... well if the doctor takes the time to listen to them, which the odd time they do... they’ll say, “oh I really like so and so...” and it’s because they listened to them... even if it’s for you know 30 seconds or a minute

*The Importance of Continuity and Knowing Well*

Support people emphasized that an essential component of both good communication and good care centers around continuity of health care providers’ involvement with people who have disabilities and the establishment of rapport that such continuity allows. The support persons interviewed indicated that most of the people they support do have a long standing family physician whom they see regularly and with whom that rapport has been well established. Having a long standing relationship provides an opportunity for a much greater level of comfort for all parties involved: “The individuals where I work have the same doctor they’ve had since forever. I mean this doctor knows them inside and out.”

On the other hand, in situations where such a relationship has not been established, there is a greater risk of communication breakdown:

People that know the guys well, the GPs, the dentists that they see on a regular basis, I don’t know about training, but they’ve got enough training from us and from the people that they’re seeing that they know the game, they understand the
situations as they arise, when you get in to see specialists, I think that’s where we run into a bit of an issue sometimes with people that don’t know the population that we support as well, but they’re getting better.

The support persons interviewed praised the efforts of those health care providers who seem to make genuine attempts to pick up on nonverbal forms of communication both in establishing rapport and in arriving at a diagnosis: “Some doctors are very good at figuring out by body language or whatever and they’ll be able to pinpoint, others just don’t have the time or inclination.”

The Importance of the Right Approach

Several support persons spoke about the tendency of some health care providers to attribute child-like qualities to the individuals they support which becomes obvious in how they address people:

What I find is, what I have found in the past is that the individuals that are supported are treated more in a child like, a youth, more like if I was to bring my child to an appointment, and they are looking for me to give information on my child. Even when I take my own kids to an appointment, especially my kids who are a little bit older, I still want and expect the doctor to have an involvement with them. And they do, so I don’t understand why that same type of courtesy isn’t extended to the individuals we support.

Another participant reiterated this claim, in describing how some health care providers approach explanations of diagnoses and treatment plans:

They, they don’t explain as fully as, it’s like, it’s more of a, and again, I’m generalizing, but I think it’s more of a pat on the head kind of, you’ll be okay,
we’ll getcha feeling better. Kind of thing, without really telling them what’s wrong with them or that’s more directly again, to the staff member.

*The Importance of Adequate Training*

The support persons interviewed indicated they were unsure about the amount and intensity of training in treating people who have intellectual disabilities that health care providers are offered in their medical training. All support participants speculated that while clear improvements have been noticed in that area, adequate training in caring for individuals with ID remains less than ideal.

No, like stuff maybe during their internship that they’ve had to have had uh, thought it was more education or, during their, I don’t know, during their time when they’re interning…more contact with, just so that they’re, you know right from the get go, before their full fledged doctors, they, they, understand that um, everybody needs to be treated with dignity and respect. And um, don’t cap somebody’s capabilities based on what you, whether how well they talk or how well they walk, or you know the look of severity in their body, the disability. Don’t put those caps automatically on those people. Maybe they should be ah, spending some time. Spending some time just actually getting to know people. Um, before they actually go into full fledged doctor’s.

*The Importance of Valuing the Individual*

Another overarching message that was relayed with strong emotion was the imperative factor of ensuring that health care providers demonstrate that the value of the individual is respected in all encounters. Instances where health care providers have
failed to do so were recalled with anger and frustration. One support person recounted a
distressing example of taking an individual to a swallowing clinic and the subsequent
poor treatment she observed:

Jane had to go to a, a swallowing clinic to check out for her swallowing
and the way they did it, it was awful. They made her eat and, uh, then, like they
had her against this board cause they would x-ray it just to see how its all going
and she had food all over her face and she was starting to feel uncomfortable and
they’re like rushing around. I said, listen, I said, ‘She can’t. Like, look at her, she
wants to wipe her face.’ Right? And it was awful… just very disrespectful too,
not allowing her to wipe…and she’s very conscientious to that…and you could
tell that she was trying to do it and they were rushing her… I said to him, I said,
listen, she just wants to wipe her face…so I’ll just never go back.

Similar to the views expressed by the individuals, staff reported that the biggest
systemic problems lie in emergency room treatment and in hospital care:

Because um, the worst thing is seeing a doctor, this happened to us a few years
ago. To an emergency ward, um, takes one look at someone and says ‘oh great,
not one of them on my shift’

The most distressing recollections made by support persons where those in which
they perceived that the individuals they supported had been denied treatment because of
their intellectual disability and the dismissal of some health care providers of the value of
the life of the individual. Thankfully, support persons indicated that such experiences
were the exception rather than the norm, but it was clear that the difficult incidents they
had experienced and recounted in the interviews had left lasting and painful impressions:
It was an individual and she’s no longer alive, umm, she had a little bump, right here, and uhh, she would hit and certain things like that, so we were like okay, that’s gotta be causing some pain, it’s getting a little bigger, and wider, and uh, she went to (city) to the surgeon there and he was just basically, “So, why would I operate on her?” “Well, why wouldn’t you?” “Well, she has a mental handicap, I’m not gonna waste my time.” “It’s like... she’s a person just like everybody else,” and we had to, that’s when we had, thankfully the parents were still alive we had them become involved and they were the ones that went in, “No this is my daughter I want it done”, and they finally did it.

Another area of concern addressed by several support persons was that of having staff in the ER ask about DNR (do not resuscitate) orders. Several support persons recounted instances where they felt DNR orders had been discussed inappropriately by health care providers for individuals who were neither elderly, nor presenting with an obvious life threatening situation. Support persons inferred that health care providers were being discriminatory since they assumed that such a question would not have been asked had the individual not had an intellectual disability:

We had that when John was in the hospital, and ‘cause he can’t speak for himself, at that point John was really sore with broken ribs, and, I remember the doctor asking me, “Do we resuscitate if we have to, or something?” And, his mother had looked at the doctor. I thought “Oh, well, yeah. I don’t know why you thought of that, but yes, of course you do”. And his mom said, she says “Oh yes you do”, he’s my son, he lives a very normal life” And he does.
Support Person Factors

Support persons themselves reflected in detail on the complexity of their role in ensuring good health care for the people they support both in and out of the health care setting. In elaborating on their role, phrases such as “being a voice,” “empowering individual,” “providing information,” “questioning necessity of treatment,” “reassuring family,” and “not overstepping” provide a glimpse into the challenging multidimensional role that support persons play in securing good care for the individuals they support.

Expectations that Health Care Practitioners have of Support Persons

Support persons perceive that health care providers expect them to provide information that is accurate and succinct in order to allow them to get a well focused picture of the issues faced by their patient who has a disability:

To bring reliable, clear, concise information on what’s going on because it’s hell for the doc to try to make a diagnosis of be giving medication for something if it is needed if they are not getting the true picture of what’s been happening.

Several participants indicated that they sometimes feel that the health care providers expect them to have greater medical knowledge than they do; one individual described how she felt that the health care providers sometimes “think of us as nurses, and we’re not,” or, that in conversation, the health care providers would sometimes refer to the individuals as “your patients” when addressing the staff.

Expectations that Individuals have of Support Persons
When asked to speculate on the expectations of the individuals they support, and how they view the role of the support professional, the key descriptors used were safety, security, and trust.

That you’re looking after it. That you’re looking after their best interest. You know there is a great level of trust between say myself and the gentleman sitting there, and he relies on me to make sure that, that I am doing the right thing for him.

What makes this especially challenging for support staff is the fact that, at times, an individual they support must undergo a necessary but painful or difficult procedure:

If I have to have something done and it’s painful? Ok, I have to have it done. You know, and I’ll deal with it. But now I am taking someone in that trusts me a great deal, and putting him, having him put through something, that he may not have a complete understanding of, and that’s, that’s difficult. It’s difficult for us to watch that too.

*The Importance of Knowing when to Access Service*

Several support persons spoke of the difficulty, as well as the great responsibility, that lies in supporting the individual in deciding when to access services. Several support persons suggested that the rule of “better safe than sorry” became an overriding factor when considering whether it was necessary to seek out medical care, and one indicated that “if anything, we probably access it too much.”

*The Importance of “Lending a Voice”*
Support persons spoke about the importance of “filling in the gaps” and “completing the picture” to ensure that the health care provider was given as much information as possible to facilitate understanding of the individual and his or her circumstances. In addition, they also have to ensure that the information is emphasized in order to ensure that nothing is neglected. According to one individual, the information that must be relayed includes:

what we’re seeing, what we’re concerned about, what we’ve witnessed, anything that we can tell the doc, anything that we take for granted. If I’m going to the doctor’s appointment, “well doctor I’m feeling this and this,” I can get a list. We have to kind of be the mouthpiece for them when we go in to make sure that the things that we’re seeing and the things they’re complaining about are brought forward and are addressed.

The Importance of Continuity and Knowing Well

As mentioned earlier, support people emphasized strongly the equally important aspects of staff continuity and the crucial importance of being observant of subtle changes in the individuals’ health; changes that may be manifested in actions and behaviours but may not necessarily be expressed in words. Being “in tune” to the individuals gives support people an ability to “pick up on” those changes and, subsequently, to respond appropriately. According to one participant, such traits are evidenced in experienced and perceptive staff:

They could just tell by looking at them...Something’s not right... So I think it’s really important that the staff is really aware of what the person has, as far as
health issues in their life and know that person well enough to know that something is off, even if the person is not saying, they’re saying everything’s fine.

In accompanying someone to a health appointment, all participants acknowledged the importance of ensuring that the support person have perceptive observation skills, is knowledgeable about the needs of the person they are supporting, and is someone in whom the individual has confidence:

It’s just to make sure that it’s someone who goes with him that’s really knowledgeable about who John is and what he’s about. Someone who he’s very comfortable with, someone that he trusts. And that, that’s the biggest thing.

Right?

*The Challenge of Dual Roles*

Support persons reported that sometimes there seems to be a struggle between ensuring good health care and protecting individuals’ rights to make choices about their life. One of the support people gave the example of the difficulty encountered when an individual chooses not to carry out a treatment that the doctor has recommended, which may be a simple action such as elevating a limb a few times a day or doing certain exercises. Her concern centered around the conflictual demands of ensuring that the recommended treatment was carried out, and respecting the choice of the individual to decide for himself whether to follow through on the recommendation. She said that this difficulty was sometimes exacerbated by family members who questioned staff about why treatments had or had not been followed, and consequently, why improvements were or were not seen. She suggested that the fault for the outcome of the individual’s
decision tends to land on the staff member who risked being seen by family members or the health care provider as not doing his or her job:

So sometimes I find the hardest part of this job in the medical stuff is sometimes that too much is placed on us... like I’ve taken way too much of a responsibility with some of the individuals that can do it themselves...that they need to do it themselves, and they’re not doing enough...and then I feel like it’s our fault if something happens. Like what’s gonna happen if we’re persistent in getting him... “okay you’ve gotta elevate or you’ve gotta lay down or whatever”, but sometimes it’s like you’re almost doing everything you can but some situations are just not healing up ...and I always feel bad and think what happens if something happens, and we’re gonna get blamed for it, you know...meanwhile, we’ve done everything we could but it’s just not going away.

When asked if there was anything that he would want to relay to health care professionals in order to see a continued improvement in the care offered to individuals with disabilities, one of the support persons gave the following articulate summary:

If I was to tell the doctors anything? It’s just keep progressing the way they are going and just to keep letting..., keep them involved. Keep the guys involved, just keep that open line because it’s gotten better, you know, there is always room for improvement in everything but, it’s gotten a lot better. You know, that the doctors have done much better than they used to and that is no knock on their abilities as physicians, it’s more, as far as... Heck, sometimes the doctor is even a bit afraid of these guys, (laughter). You know, because they don’t know, they don’t know what they’re about, they’re different you know? They’re people, they’re you and
I, but they’re... a different walk of life. You know it’s like, different. Sometimes it’s almost like dealing with a different culture, because they don’t present the way you and I present, they don’t you know maybe talk the way you and I talk...

But things have changed.

Interviewer: In the right direction?

I think so, I think so. There’s still some space to go. Still some improvements to make. But, ah, as long as we’re advocating and as long as the doctors are willing to listen to us... And as long as these guys are allowed to speak. They got lots to say. Just listen.

Perspectives of Health Care Providers

System Factors

The health care providers who were interviewed articulated their concerns thoughtfully regarding system barriers and their frustrations in attempting to provide great care within the confines of a less than great system.

The Concern Regarding Time

Of primary concern was time which, perhaps surprisingly, was mentioned more often and with greater emphasis by health care providers than by either of the other two groups of informants. Several of the health care providers said their personal experience was that caring for persons with ID necessitated a longer appointment time than might be allotted to some other patients.
Having enough time to work things out with somebody is key, you know. If a doctor, if a health care provider is working in an environment where they feel rushed or pressured, I can’t see how that is going to work very well. I just think that’s going to be a good barrier to good quality care for somebody, you know, with any kind of complex problem, particularly for people with developmental disabilities.

However, one of the health care providers suggested that this was not always the case and that the perception of needing extra time and additional expertise is a commonly held but sometimes incorrect assumption. As one of the health care providers interviewed stated:

The perception is that it may take more time, and in some instances it might. But in other instances it doesn’t necessarily have to, if you have the right information.

So that sort of is a deterrent for a lot of physicians

*The Concern of Adequate Remuneration*

From a pragmatic perspective, billing systems for physicians can act as a barrier since providing care for someone who may take more time in consultation than is allotted under the Ontario Health Insurance Plan guidelines can be a disincentive. Of the health care providers interviewed, some had the experience of working in community clinics while others had private practices. One of the health care providers who worked in a community health clinic and was paid by salary expressed what he saw as a perceived luxury of being able to plan for a 30 minute appointment, but said that even so, the time was sometimes insufficient.
I mean you come in with a sore throat, a person with a developmental delay comes in ’cause they’re not feeling well or not looking right, I get the same fee whether I treat you or whether I treat somebody who’s very much more complex. It was suggested that the perceived need to allot a longer time for consultations might be a deterrent for physicians who would receive no greater remuneration for treating someone who may take longer to assess. One suggestion was that creating a greater financial incentive and making changes in the funding model for physicians would encourage more physicians to accept individuals with ID as patients, and would also allow them to take the extra time needed in consultations without feeling that they were going to lose out financially by doing so.

So I think if the government gives more funds to physicians it’s just natural they would reconsider that, because the work then, the compensation sort of offsets the extra work, if you will.

The Concern Regarding Shortage of Family Physicians

The importance of continuity of care was widely reflected in the responses of health care providers. In particular, they emphasized that a lack of continuity in medical care is a significant barrier to establishing good communication and subsequently good care for patients with ID, as it is for all patients. The shortage of family practitioners currently experienced throughout Ontario contributes to the challenges of ensuring continuity.

Essentially in a very busy office or a busy clinic or a walk in clinic type thing, it’s very difficult [to ensure continuity] as well as that with the shortage of family
doctors you find people with a developmental disability are kind of being trucked from pillar to post and never see the same doctor twice.

And as you know there’s this incredible tendency to add medication rather than subtract, so you can end up dealing with a whole bunch of medication and side effect issues and totally ignore what the person came for in originally

_The Concern Regarding Continuity of Care_

A concern about inconsistency in care and, in particular, the lack of medication management that would follow from it was expressed by several health care providers.

One informant suggested that the way to best resolve this would be to ensure that individual patients receive care from a health care provider who is closely familiar with their needs, and who is willing to provide the much needed continuity. In describing the importance of such a relationship, the term ‘medical home’ was suggested:

The other sort of systemic issue, is the need for, in the States they call it a medical home, and somebody who takes responsibility to ensure that all the medications are reviewed regularly and those things that are, that were instituted in a crisis are not necessarily ongoing but are reassessed. Because that is another problem that can happen is that people get on just too many medications and they are not being reviewed and pared down. And somebody just has to take responsibility for that.

And, you know, again it is having that home. And if you don’t have a home it is easy to get lost. And also important information gets lost and just to qualify that, I think the point is there that it’s not just anybody, there is a service that is primary care, and it is not to think that that is exchangeable, that it doesn’t matter who
provides it I think it does. I think that is more of the relationship that is important and that gets beyond just a bunch of services and records.

*The Concern Regarding Lack of Psychiatric Outpatient Care*

When asked to suggest the biggest gap in service provision for the people with ID in their care, the unanimous suggestion was lack of psychiatric care. One participant described finding someone with experience in dual diagnosis who was also willing to accept clients could best be described as “an absolute nightmare.” All of the health care providers interviewed expressed clear frustration and concern for their clients given the difficulties in finding appropriate care.

And for a lot of psychiatric disorders, I guess like schizophrenia or depression or whatever, it’s difficult to get a timely psychiatric assessment, follow up and so on. But it is possible and it sort of feels like there are lots of psychiatrists out there who can help with those problems. But for somebody with an intellectual disability plus a psychiatric diagnosis… it just seems that the number of psychiatrists who know how to approach that is incredibly small.

*Individual factors*

While medical practitioners stressed that most of the obstacles related to securing good care do not reside within the people themselves, they also reiterated that communicative challenges faced by some individuals cannot be overlooked as a contributing barrier, as the examples that follow demonstrate.

*The Concern Regarding Ability to Take in Information*
Health care practitioners recognized that an individual’s ability to understand information had the potential to influence health care outcomes and that this varied greatly from one individual to another:

In terms of giving information to the client, the main barrier I think is determined by their intellectual abilities, or their ability to, person’s ability to take in information, understand it and um, act on it. You know, and that’s a, you know, it’s just not the same for everybody.

But I don’t think there’s any way around acknowledging that’s a huge barrier.

You know that’s a big issue.

The Concern Regarding Anxiety and Fear

Like the support staff participants, health care providers expressed identified anxiety and fear as being tremendously inhibiting for patients with ID. Informants emphasized that finding appropriate ways to alleviate patient fears and concerns was an important practical skill for health care providers and community support persons alike:

Sometimes getting, even getting diagnostic tests and doing procedures can be difficult, you know, if you have somebody really anxious or agitated and they can’t sit still or lie still for a CAT scan or for blood work, you know, terrified of needles or um, procedures like pap smears or whatever. I mean that becomes a barrier too.

The Concern Regarding Lack of Assertiveness
Health care providers also alluded to their concern that the health care system tends to be reactive to advocacy so that individuals are expected to know how to ‘work the system’ to get what they need. However, individuals with ID often have to negotiate the health care system with the advocacy help of another person. As one participant said, “So you know, it depends on other people, they depend on other people who know the system and know how to work it and advocate.” This ties in with the assertion made by several health care providers that people with ID usually have not had the opportunity to act as active agents in health care situations and, therefore, may lack the assertiveness skills needed to articulate their needs:

And most of the people with developmental disabilities that I have known are not very aggressive on their own behalf. I mean, you know they may, not be aggressive on behalf of their own care.

**Support Person Factors**

The health care providers interviewed, acknowledged the essential and complex role that support persons provide, and stressed the importance of valuing support persons as an integral part of the health care team. As one health care provider stated:

Don’t underestimate the value [of] community support workers, you know, listen to them, talk to them, they’re your biggest allies.

Health care providers also recognized that often this is not an easy role to negotiate.

Yeah, and it’s a constant balancing act because um, you know, where you need to be in that depends a lot on the functional abilities of the particular client. And the abilities of that client in view of the particular issue or problem that they’re
dealing with, like there maybe some issues of problems where they’re perfectly capable of dealing with independently, but then another thing comes up and you know, the worker needs to be a bit more involved. Or the issue is not just something that affects the individual client, it’s also affecting, directly affecting, the well being of the worker or the safety worker. The well being of other people in the house, um, it can be a bit more, you know, so, yeah it’s constant negotiation

**Importance of Continuity of Support Person**

Continuity of support persons was described as being vital to facilitating health care support and making health care consultation easier for the individual and health care provider alike.

Continuity is big, continuity with the physician is important. Continuity with the support, care givers, their support is equally important.

And so if you had someone who’s been with a person for several years, they’re much more in tune with that person as opposed to having someone who’s just there episodically. And they don’t have the same knowledge and that sort of thing.

Another health care provider further reiterated the importance of continuity and pointed out the impact it has on care.

There’s always a big difference in the quality of information you get from a worker who you can tell is tuned into the individual we’re working with. And I guess by that I mean there’s somebody who’s observant and somebody who cares.
And somebody who can articulate what they’re observing and because they’re often, they’re the ones who are almost going to voice the concerns that the client.

Several physicians emphasized that continuity of support persons made a tremendous difference in the consultation itself as those who knew the individual longer and more closely would be able to provide more complete information than staff who did not know the person as well. In addition, having a support person with whom the individual had a positive relationship could have a great impact on the dynamics of the interaction and affect the comfort level of the individual during examinations. Those support persons who had the greatest positive influence were described by one health care provider in the following way:

Well, they’re just more in tuned with their patient and they’re not...some of them it’s just a job and they’re just there, and others they’re sort of, they know the person, they’re concerned about their well being. Uh and they bring good information and uh, you know they’re doing their job.

*The Importance of Support Person Knowing Well*

The sense of “being in tune,” “geared to the patient’s needs” and able to pick up on subtle changes in an individual’s health were reported to be extremely important attributes for support persons. Furthermore, the support persons’ knowledge of the health history and background of the individual was relied upon heavily by the health care providers who were interviewed. While participants stressed the need to seek out as much information from the individuals themselves as possible, the information provided by the support persons was described as being key to ensuring that a full picture of the patients’ needs was obtained:
Usually I would direct most of my questions and all the beginning questions to the patient first and then look for fill in as appropriate. ...the support worker really is key to it, because if you’ve got a good support worker that you have worked with before, that you trust, and who has a pretty good idea of what you’re looking for, you will get most of your information through them.

The health care providers interviewed also indicated that they respected and appreciated support persons who were concise in articulating their concern, and who ensured that their “hunches” that something was not right with the individual were taken seriously and investigated appropriately:

I mean the support worker has to be both the voice for, but also the advocate for.

And you know, if you don’t seem to be getting the point, they really need to kind of stress what their agenda is as well. Because sometimes, you know, sometimes we would minimize some of the things that come in, and see it as not a big deal, and if they think it’s a big deal, well then it’s their job to bring that forward.

In contrast, having a support person present for a consultation who did not have a good knowledge of the individual they were accompanying was described as a source of frustration:

It’s really helpful when they, family member or the residential worker who comes along, a lot of it is obviously if somebody knows the client well, not a somebody who’s just there for a temp shift for the day...

My experience is that, you know, that the visit is going to be way, way, way more useful if the client is accompanied by somebody who knows them well. Well you
know, I have some clients who come on their own. But the ones who needed somebody to come along, it’s night and day you know.

(Interviewer) Were there times when someone said I just came, I don’t really know this person? )

Yeah lots of times. Lots of times, you know sometimes you just…well it can’t be helped. You know the regular worker was sick, there’s another crisis at the house, they just had to send somebody else along…. But it’s almost, well you know, it’s just very difficult then. Very difficult. Very frustrating

The Importance of Implementation of Care

The health care providers interviewed also stressed the obvious role that support persons have in carrying out the recommendations and the agreed upon health care plan that is determined in a health care consultation. While health care providers can order medications and treatment regimes to be followed up at home, it is ultimately the support person who will ensure that the plan is carried out. It is therefore important that the plan of care is something that all parties are in agreement with. One health care provider stressed that adequate training, therefore, must not only be directed to primary health care providers, but also to support persons who will ultimately be responsible for the implementation of care:

And another thing, it is very important what they think works.

And if you just deal with the primary care providers and basically just tell them that often they are not either medical or ethical justification for say the use of antipsychotics for behavioural problems they can accept that but every time they try to make some changes it can be undermined by support workers who can’t
accept that. Who don't see it, who don't believe it or who just don't think it will work. It can sabotage any attempts to change inappropriate medications. That's how important their role is.

The Concern Regarding Unrealistic Expectations

While the medical professionals interviewed emphasized the importance of the role that support workers play in facilitating the health care of the people they support, they also expressed frustration with what they described as some unrealistic expectations the workers had of the health care system:

Well sometimes umm, you get the feeling from some of the staff particularly in some of the homes we have and some of the people with very challenging needs that its they almost expect a miracle that I'm somehow or other going to be able to magically be able to give them a pill which will control all sorts of behaviors, whereas as we know, behavior is a form of communication and it takes a lot longer to fish out why the person is doing this rather than just giving them a pill to stop it and sometimes I think the staff get a little frustrated that we're trying to find out why X is doing Y rather than just giving them a pill and letting them go back to whatever they were doing

The Importance of the Association and Adequate Training

One health care provider indicated that the philosophy of the local Association for Community Living, and the time and resources invested in adequately training support persons, had a significant effect on ensuring good care for people with intellectual
disabilities. In addition, this participant emphasized that having high expectations of support staff has the desired effect of achieving a higher standard of care:

I think it really is the philosophy of the association and the fact that they spent a lot of time training staff and have very high expectations of staff and I’ve found if you if you raise the bar and expect people to hit it, they tend to.

Health Care Provider Factors

The Importance of Tailored Communication

Health care providers spoke about the importance of being aware ahead of time how the person communicated so they could be prepared as much as possible in how to best tailor their communication to meet the individual’s needs. Health care providers stressed the importance of not underestimating individuals’ ability to express themselves, or to understand information;

Although, for the communication piece I think it is part of the basic data, that you have with anyone that you know if they have an intellectual disability that you know what level they are at and, it should be helpful to have what is a reasonable expectation as far as communication for somebody at that level.

And I think that, you know, many family doctors deal with kids all the time so they communicate appropriately but, I think the thing that is a bit tricky is that when you are dealing with an adult you don’t have those visual cues that you have with kids, I think, automatically, to pitch yourself at the right level.

Having an awareness that some people may have the tendency to acquiesce was also identified as being essential.
Um, you know just knowing the individual client is so important because you know, somebody, you just know some of your individuals will agree to anything that you ask them. And, you know they'll just say yes to anything.

As an informant noted, some individuals may also give the impression that they understand when, in fact, they do not because they believe it is what the health care practitioner would want; “Well, I think it’s that, well first of all, that they recognize that people can make gestures as though they understand and they don’t.”

Health care providers suggested that having some understanding of the individual’s level of understanding and communication preferences in advance would start consultations off on a much more positive note.

*The Importance of Ongoing Relationship/Continuity*

Health care providers clearly stressed the vital importance of individuals with ID having access to health care providers who know them and with whom they have an ongoing relationship. This was highlighted as a key factor for a number of reasons. They stressed that if the health care provider the individual is seeing is familiar to them, the encounter would be more “relaxed,” the individual would feel more comfortable and at ease, and would be more likely to “communicate better and more.” In addition, familiarity allows health care providers to take greater notice of their patients’ changes in behaviour, demeanor and mood. Furthermore, health care providers warned that lack of continuity in care, particularly regarding medications, could be seen as unsafe:
Changes in behavior, changes in demeanor and mood. You know, when you’re working with a lot of different, different medications, if there’s too many care providers involved, there could be, you know, medications can get screwed up, a lot of medications like for psychiatric diagnosis, you have to be very patient, you have to increase doses slowly, introduce new medications slowly, taper them slowly. You have different people thinking no I think it should be this, or I think it should be that, you know, you can get a health care plan that doesn’t have any consistent direction. And, it’s not likely going to work well and it’s a bit dangerous.

A significant factor contributing to a sense of success for health care providers is the development of rapport and a sense of connectedness in their relationships with the individuals they see in their practice, as the following narrative illustrates:

The factors that would contribute to the success…it would be working in a context where you can develop a long term relationship with somebody, so you get to know them, you get to know their family, um, and you get to know their workers, you know, there’s just satisfaction in developing a comfortable relationship, that’s very satisfying….

It’s rewarding when you get results, you know, when you meet somebody new and they’re having some difficulties, somehow you manage to help out and improve their quality of life. Yeah, it’s very rewarding.

*The Concern Regarding Wrongful Assumptions*

Health care providers suggested that some of their colleagues continue to be reluctant to take on new patients with ID as there is a perception that providing health
care to these patients requires specialized training. One health care provider alluded to the current trend of “cherry picking” which allows providers to choose their patients based on the complexity of their needs and suggested that within such a system, there is a distinct preference for those patients who are perceived to be easiest to care for:

“Professionals are reluctant to see people with developmental disabilities, they feel like they can’t help or won’t be able to help or feel like it will be too disruptive or take too much time.”

While health care providers expressed that, overall, there have been many positive changes noted in the care provided to individuals with ID, they also acknowledged that there remain instances when judgmental attitudes of care providers stand in the way of ensuring that individuals get the care to which they are entitled:

But sometimes you still do run into issues and people are judgmental sometimes and they’re making calls that they shouldn’t be. In terms of decisions, you know whether a person is entitled to have a certain surgery or whatever. They’re relatively few, but occasionally people make judgments or they don’t, they’re not in a position or have the right information to make those calls.

The Importance of the Allied Health Care Team

Health care practitioners also stressed the importance of recognizing the larger health care team, nurses, therapists and pharmacists, and reiterated the importance of consistency in care in this larger systemic context:

Um, you know, I think, you know another part of that consistent team needs to be a pharmacy, so that all medications are all coming from the same place, they’re
always checking for cross reactions and allergy histories and I think that’s an important part of the consistency as well.

The health care practitioners also recognized the need for a wider range of health care team members to gain a greater understanding and comfort level in providing care for individuals with ID, as the following quotation illustrates.

Just I think broad familiarity, among health care professionals. You know, nurses, in emerg departments, um, nurses in inpatient wards, doctors in hospitals. You know, just kind of a comfort level and a kind of interest and willingness to work with folks.

The Importance of Adequate Training

Health care providers emphasized that adequate training for all health care professionals is essential and is becoming increasingly recognized as relevant and important. However, they also suggested that current medical training still has gaps.

I don’t think our training prepares us very well to work with people with difficulty communicating or people who have to take extra time. And um, so it can be a bit scary ah, to be presented with somebody who has complex problems on multiple medications that you have difficulty communicating with. Um, sort of a scary position to be in as professionals, you just feel like it can be so easy to make a mistake and so hard to do something right.

Health care practitioners expressed that, while a greater amount of training is needed early in the education of health care professionals, there has been a positive influence on the attitudes of health professionals as greater inclusion is seen in school systems and society as a whole.
I think some of it has to start at the undergraduate level. I think some of it is happening in society. Remember that most people who are just into a medical career, like people in their 30s, 40s and early 50s had very little exposure to people with developmental delay 'cause they were all in institutions
And I think it starts right down at the ground level, that when you start integrating children into a regular classroom in school, people grow up knowing someone who is developmentally delayed and suddenly they’re not “them” they’re “us”
Among health care providers, there was broad acknowledgement that communication skill development for health care professionals must be considered as an important step in improving their ability to communicate effectively with individuals with ID in their health care encounters. However, it was also pointed out that such training must involve much more than simply listing health care recommendations:

There has to be some information about what to do but there also has to be some modeling and some feedback on people actually doing it so it is a big job.
Because a lot of it is habitual and unless you are used to you know, shifting gears and talking to people and making sure that they understand you and are giving you the feedback that you hear from them to validate and verify that you are actually getting through, it’s not an easy thing to learn I think.

The Importance of Valuing People

Of fundamental importance to the health care providers interviewed was the need to see “people as people” and to ensure that the underlying assumption that drives their interactions is that individuals with ID are valued. As described by the health care
providers, this involves taking the time to genuinely listen to people’s concerns, and to appreciate each person’s unique circumstances:

B (Participant) I think the key to it though is seeing people as people. If you don’t have that philosophy in the first place, you’re never going to get very far with treating people with a developmental delay because if you don’t value their lives like anybody else’s life, you’re behind the eight ball.

A (Interviewer) Treat all people the way you want to be treated.

B Yeah.

A I mean that’s pretty basic.

B It’s pretty basic but it’s amazing how unbasic it is to some people

The health care relationship has a reciprocal aspect as well. Health care providers recalled the positive rewards that they have experienced in caring for people with ID:

And you know, sometimes if you make a diagnosis, or whatever and it makes a difference, but they’re very genuine people sometimes, and they’re very vulnerable and uh, so I enjoy it from that perspective, so sometimes I’ll get a response from them, that the caregivers go wow, I’ve never seen them do that before which is sort of, means a lot, they can be a very enjoyable population to work with.

As one of the health care providers emphasized, valuing each individual by creating a genuine relationship is at the root of ensuring good care:

And that, in a sense that is the beginning point and maybe even the end point but it is actually to kind of connect with people or just appreciating them as people.

And helping them out as best you can and secondarily, comes the technical
knowledge. I think if people had that connection and that rapport, that they are able to establish, and possibly that happens best and earliest outside of the medical context. And when it comes to helping out with the medical things it won’t be difficult and they will be motivated to figure out what might be a little bit different for this person than for the next patient.

DISCUSSION

Being Well Bemet

When asked to reflect on those attributes and qualities that health care providers should possess and enact to create an ideal communicative environment, participants in all groups actively contributed towards an extensive list. Interestingly, there was considerable agreement among participant groups on just what constituted such qualities (see Table 3).

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<tr>
<th>Individuals</th>
<th>Support Persons</th>
<th>Health Care Providers</th>
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<tr>
<td>Available easily</td>
<td>Accessible</td>
<td>Don’t be superior</td>
</tr>
<tr>
<td>Being friendly</td>
<td>Accomodating</td>
<td>Value individual</td>
</tr>
<tr>
<td>Being helpful</td>
<td>Friendly</td>
<td>Make friends</td>
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<tr>
<td>Non-judgmental</td>
<td>Compassionate</td>
<td>Form relationship</td>
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<tr>
<td>Cares About You</td>
<td>Shows respect</td>
<td>Simplify explanations</td>
</tr>
<tr>
<td>Straightforward</td>
<td>Explains procedures</td>
<td>Careful observation</td>
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<tr>
<td>Joking</td>
<td>Patient</td>
<td>Use persons name</td>
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<tr>
<td>Knowledgeable</td>
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<td>Doesn’t rush you</td>
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Table 3 Positive attributes and qualities valued in health care providers by participant group

Comparing these lists to criteria mentioned in the general health care communication literature can lead to the speculation that these might be considered generic or universal and perhaps they reflect those qualities that anyone, regardless of ability, might welcome in a health care encounter. Highlighting these commonalities should in no way cause us to dismiss their importance. In fact, it serves to do exactly the opposite. It points out that while we may differ in our preference of how we are responded to in health care settings, there are universal approaches that all of us want and expect from our health care provider.

Individuals, support persons and health care providers alike suggested that, at the core, the values that lead all health care encounters should parallel those offered to all persons regardless of ability. However, it was also emphasized strongly within the responses that individuals with ID are more vulnerable and, while their expectations relating to health care encounters may show strong commonalities with those of the general population, the fulfillment of these expectations is not always a reality.

The Concept of Being Well Bemet
To try to encapsulate the range of qualities described by the participants, and to further explore their relationship, I have chosen to adopt a popular word used in the health communication literature in my native Sweden but one for which I, and several other authors, have failed to find a direct suitable English translation. The phrase “bli bemott” directly translates as “to be bemet.” However, the only use of this word in English that I was able to find drew me down an off-course path to Shakespeare’s King Lear in which the Duke of Albany exclaims “Our very loving sister, well bemet” at the arrival of Goneril (Shakespeare: King Lear, Act 5 scene i). However, in Swedish, it is a useful and descriptive term and one which I believe warrants adoption in this discussion. The Swedish Academy’s Word List (Svenska Akademins ordlista) defines it as “acting towards, treating or behaving towards” (SAOL, 2007, cited in Larsson and Lindahl, 2005, p. 1) in the context of service provision. As Lindberg explains in Socialstyrelsens Institut for Sarksild Utbildniumsstod (National Agency for Special Education and Support) SISUS (2001),

We have all had the experience of meeting someone in a genuine way. The conversation flows effortlessly and even silences are a comfortable part of the conversation. It is often that way when we meet with friends or loved ones. ‘Being bemet’ is something quite different. The concept is not one of simply meeting someone – at least not on equal terms. It is because the term implies a power differential. It is when someone in a role of power or authority ‘bemoter’ someone else. For example, a doctor with a patient. (SISUS, 2001 p. 42)

This description points to the asymmetry in the relationship between doctor and patient in terms of formal roles. However, fundamental to ensuring someone is well bemet is a
recognition that, despite that imbalance, there is a recognized equality of individual worth. At its core, being well bemet means that everyone should be valued for who they are, in other words, their intrinsic dignity is respected. Regarding the meaning of being well bemet, Jonsson in (SISUS, 2001) makes the suggestion that “perhaps it is just simply seeing yourself in the person you are meeting” (p. 18), recognizing someone as a person, not equal in role, but equal in worth. Being bemet is essentially a two dimensional experience in one word. It can be described both as how you approach someone (the values you bring with you), and how you respond to someone (how you enact those values in a particular encounter).

The Importance of Consistency in Approach

In terms of how someone is bemet, the findings of the current study suggest that there are clear and distinct commonalities that should guide the approach of health care providers in all encounters. The following excerpts from two different health care providers interviewed illustrate this notion:

I think the key to it though is seeing people as people.

If you don’t have that philosophy in the first place, you’re never going to get very far with treating people with a developmental delay because if you don’t value their lives like anybody else’s life, you’re behind the eight ball.

But generally I treat them as I would any other patient. You treat them with respect and dignity and you get results. So, yeah, I just, they’re as deserving as anyone else for good health care. So give yourself enough time, expect some
rewards. Try to approach the client like you would anybody else about age and gender. You know what I mean?

The meaning implied in these quotations reflects the understanding of seeing the “sameness” in individuals with ID in terms of value and worth. The health care providers interviewed emphasized the importance of approaching people in a way that shows that they “value their lives like anyone else,” “treat them with respect and dignity” and thereby “approach the client like you would anybody else” which is the foundational basis of ensuring someone is well bemet.

Blennberger (2005), who has explored this concept in detail, places emphasis on the components that he suggests are key to ensuring that someone is well bemet. Drawing on his work, I have highlighted several of these components as they relate to the articulated key concepts suggested by participants.

Respect is an imperative concept that Blennberger suggests is enacted within a service context as showing an attitude of consideration and courtesy, also implying a nonbiased or nonpartisan way of treating someone.

Equality – Respect includes a dimension of equality. Blennberger distinguishes between equality and symmetry and points out that, in a service provision context, the relationship is, by it’s very nature, asymmetrical in that one person needs something from the other (such as health care service) but the person with greater power must acknowledge that despite the asymmetry of our positions or roles, I see you as a person of equal worth.

Kindness – Blennberger makes the suggestion that respect, when taken independently, can give the connotation of reservation and professional distance. He
therefore suggests that a word expressing human warmth is necessary to fulfill the description of being well bemet.

Trust – Blennberger proposes that mutual trust is another important component of ensuring that someone is well bemet, as opposed to having an attitude of distrust or suspicion.

Empathy – According to Blennberger, empathy serves a dual purpose. On one hand it suggests being attentive, interested, and listening actively; on the other, it implies an ability to put oneself in the other person’s position and to look at things from his/her perspective.

Humour and Ease – By Blennberger’s criteria these suggest a level of comfort and the ability to share in seeing the lighter side of things.

A summary of the traits commonly reported by participants in the present study is included in Table 3, and are highlighted to show their commonality with Blennberger’s descriptors. These traits were expressed by participants in all three groups as being enacted in health care encounters in tangible ways such as eye contact, addressing the patient by name, positioning oneself in a way that emphasizes equality, speaking directly to the individual, joking, and taking time.

The Importance of Uniqueness in Response

While participants affirmed that there are universal principles in good practice, an equally important concept articulated by participants is recognizing uniqueness in all persons, i.e., in the response component of ensuring that someone is well bemet. In this
context, treating everybody the same can have two very different and negative connotations as compared to the positive values listed above.

**The Risk of Not Meeting Individual Needs**

Individuals with ID face the risk that Heyman, Swain and Gillman (2004) refer to as “organizational simplification that can lead to secondary complexities” (p.357). They define these as instances where, due to restrictions such as resource pressure, health care is routinized according to a standardized patient model, and those who fall outside of that model cannot have their needs met adequately. Clark (2004) describes this tendency by health care providers who, rather than listening to patients’ unique needs, say “here is the box, make yourself fit in” (p. 728). In the interviews, a frequently mentioned example of this issue was that of lack of time in consultations. It is interesting to note that it was the health care providers who stressed this concern more than the other participants. Both individuals and support people did describe times in consultations when they had felt rushed. They expressed the feeling that the health care practitioner had “their hand on the doorknob.” However, it was the health care provider group who more strongly emphasized the lack of time as a serious potential barrier to effective communication and effective care.

Trying to establish a correct diagnosis and appropriate treatment with someone who might require more time than the “average patient” could lead to “short cuts in care,” as several health care providers suggested in situations such as examination, and in ensuring informed consent. Physical or communicative limitations could both mean that standard routines would compromise care. Health care participants described their
concerns by saying: “Again, you know, if somebody’s difficult to move or shift around or undress, chances are a lot better that you won’t do it.”

But having enough time to work things out with somebody is key, you know. If a doctor, a health care provider is working in an environment where they feel rushed or pressured, I can’t see how that’s going to work well. I just think that’s going to be a barrier to good quality care for somebody, you know, with any kind of complex problem, particularly for people with developmental disabilities.

Another health care provider recognized a similar concern.

Well, I think a big challenge is the time constraint. And I guess my concern is when it comes to things like consent. In a sense that is a bottom line issue because it involves a whole process, part of which is making sure that people understand what the problem is and what the options are and that they have some say in how things evolve. It is a bit of a time consuming process. So I suspect that it doesn’t happen routinely. If you were to look at how the process actually works, out in practice it is short cut. There are all sorts of short cuts.

Health care participants related the lack of time to a fee-for-service model in which there are essentially disincentives created for patients who may take longer time to communicate their needs. Such concerns strongly suggest a need to examine infrastructure and funding policy changes. The following excerpt reiterated that concern:

“I mean you come in with a sore throat, a person with a developmental delay comes in ‘cause they’re not feeling well or not looking right, I get the same fee whether I treat you or whether I treat somebody who’s very much more complex.”
Support persons emphasized the importance of having health care providers talk with the individual directly at the onset of a consultation. However, they also suggested that health care providers “speaking past” the individual and addressing questions to the support person instead, was not always done out of disrespect but, rather, “in the interest of time” suggesting a belief by support persons that resource restrictions necessitated health care providers’ turning to the support person for information to expedite the interview. This exemplifies the form of standardization that Heyman et al. (2004) suggest is “driven by the need of human service providers to process clients en masse with limited resources” (p. 365).

The Risk of Stigmatization

Another risk is that of stigmatization and stereotyping, or treating someone the same as everyone else with ID. Norms, attitudes, preconceptions and power-relationships all influence how someone is betmet (Samarbetsorgan for etniska organisaskoner i Sverige – The Cooperative Group for ethnic associations in Sweden - SIOS, 2004). We are influenced by societal influences on our own thoughts of what people with intellectual disabilities are like. The easiest way to try to understand is to simplify and standardize care. However, by simplifying too much we can create stereotypes and treat people with a certain attribute as if they were representatives of an entire group. “We place greater emphasis on the functional disability than on the person who has it” (SIOS, 2004, p. 9). Individuals with ID cannot be classified in a homogeneous category. Doing so can lead to the belief that they belong to a certain group of people who should be
treated in the same way. Such preconceptions about the "group" make the individual irrelevant. (SIOS 2004) When a person is labeled in this way the label can obscure accurate perception of the individual suggesting that people with ID "are" a certain way and therefore should be bemet in a particular fashion (SOIS, 2004). In contrast to this homogenous approach, participants stressed the importance of recognizing significant variation in wants and needs of individuals. Failure to do so places individuals at what Shapiro et al. (2003) describe as "the risk of being invisible, devalued and being treated perfunctorily and dismissively" (p. 640) in their health care encounters.

The most distressing recollections of poor treatment reported in the interviews were those that clearly indicated the failure to both approach and respond appropriately to the individual. These were occurrences where the person's human value was questioned and his/her unique needs disregarded. Support persons gave examples of instances in which they felt the need to defend the person's right to be addressed directly, to be treated respectfully, and sometimes to be treated at all, as the narratives recounted in the findings revealed.

*In Summary – Being Well Bemet*

Bennberger's (2005) universal approach coupled with an individually oriented response can, therefore, ensure that someone is well bemet. To see the unique individual needs and possibilities ensures someone is well bemet which, in turn, sets the stage for constructive communication. Any attempts at being overly prescriptive in the mechanics of communication with any group of people identified by virtue of a particular characteristic should be approached with caution.
People are alike in value and worth, unique in needs and, and therefore must be bemet as such. In his white paper “Fran Patient till Medborgare - From Patient to Citizen” Lars Enquist (1999), then Swedish minister of social affairs, made the following observation:

Being well bemet is about all peoples’ equal worth, it is about everyone’s right to be respected and accepted as they are. Each and everyone one should have an opportunity to grow as a human being, together with others. Have power over their life. Be seen as a person with knowledge and experiences. Not have to be treated as incompetent or childlike. Be missed when there are barriers for full participation. (Enquist, 1999, p. 79)

Reading the description above could lead one to further draw the conclusion that part of ensuring someone is well bemet is enacting the principles of inclusion. As Law et al. (2005) describe ”openness, respect and a culture of equal opportunities create the conditions for inclusion. The extent to which the service user perceives his/her views to be respected and recognized by others provide a measure of inclusive practice” (p. 174). Further complementing Law et al.’s definition, Heyman et al. (2004) state:

Inclusion is based on the positive valuing and celebration of difference. Inclusion requires acceptance of the rights of people with learning disabilities to have their needs met in mainstream services, adoption of a welcoming approach to people with complex health needs, and long-term organizational change which acknowledges uncertainty about complex phenomena. (p.365)

Shakespeare’s phrase “My loving sister, Well bemet!” in Sparknotes “No fear Shakespeare’s” practical modern language translation reads as follows: “My dear and
loving sister in law, I am happy to see you.” When asked what made his encounter with his health care provider a positive one, one of the individuals interviewed said, “he always has a smile on his face when he sees me... when I arrive there so, so it’s almost like he’s glad to see me.” Without getting lost in translation, I believe his statement similarly echoes the importance of feeling well bemet.

Being well known

Within the general health care communication literature, authors have placed emphasis on the importance of establishing rapport and a sense of connectedness in caring for patients. Many of these authors have made recommendations on how to best establish such a connection within the context of “knowing the patient” (Liachenko, 1997, p. 23). “Knowing the patient” is a recurring theme in the health care literature although exactly what is meant by the phrase varies within and across research domains (Liachenko, 1997; Thorne et al. 2005). The findings in this study, echoed among each participant group, provide convincing evidence that this connectedness and knowing is a fundamental value in supporting good communication for individuals with ID.

The concept of being well known

Grant (2005), drawing largely on the work of Liashenko (1997) as well as Mead and Bower (2000), summarizes four levels of knowledge:

‘Case’ knowledge implies the generalized, or biomedical knowledge that has to do with a theoretical patient, rather than an actual individual. In fact, Liachenko (1997) describes this as the “disembodied patient” (p.24). It reflects a knowledge of etiology, clinical symptoms and prognosis (Grant, 2005) and reiterates what Gadamer (1975) refers
to as ‘objective knowledge of the other.’ In other words, knowing a patient in this way places that individual in a passive position, an object upon which the health care provider acts (Liachenko, 1997).

‘Patient’ knowledge, a kind of knowledge that requires ‘the particularity of a body’ (p. 26), includes knowing something about the individual person’s story, his/her history and demographics, and even that person’s physical and emotional responses to treatment.

Adding to Liachenko’s model, Grant (2004) contributes an important addition in suggesting ‘Communicative Knowledge’ as ‘how people convey intent, meaning and understanding.” (p. 713). He further states that this is of particular importance for those whose verbal abilities may be impaired, “making assistive communication technologies, allies and advocates important” (2004, p. 713).

‘Person’ knowledge, the final form of knowledge in Liaschenko’s (1997) model, focuses on knowing the person, “as a subject who acts with her or his own desires and intentions” (p. 26). This represents knowledge that implies understanding how the person is situated in the world and how he or she engages in that world. From Liaschenko’s perspective, the ideal situations are those which integrate all of these forms of knowledge. In reflecting on this integration for people with ID, Grant (2005) states, “In the present policy climate where such a great emphasis is placed on the forging of partnerships between doctors, health and social care workers, patients and families, all of these types of knowledge have to be brought into the equation” (p. 714). Grant further suggests a simplified representation of how these differing forms can be visualized (see Table 4). Its relevance in the present discussion is clear.
<table>
<thead>
<tr>
<th>Type of knowledge</th>
<th>Person as expert</th>
<th>Family as expert</th>
<th>Practitioner as expert</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case – knowledge</td>
<td>Low</td>
<td>Low</td>
<td>High</td>
</tr>
<tr>
<td>Patient knowledge</td>
<td>High</td>
<td>Medium</td>
<td>Medium</td>
</tr>
<tr>
<td>Communicative knowledge</td>
<td>High</td>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td>Person knowledge</td>
<td>High</td>
<td>High</td>
<td>Low</td>
</tr>
</tbody>
</table>

Table 4 Knowledge, the person, the family and the practitioner (Grant, 2005, p. 714)

As Grant has described, person knowledge and communicative knowledge are the domains in which individuals themselves will have the greatest knowledge. Their support persons may also have insight and understanding in this area, and likely it is greater than that of the health care professional. This domain is probably the area in which health care professionals are least knowledgeable. Patient knowledge is also a domain in which the individual may have greater knowledge than the other stakeholders, although this may be dependent on the extent of their disability and need for support. Case knowledge, finally, is the most obvious domain in which practitioners will have superior knowledge.

It is important to avoid oversimplifying these descriptions as positive or negative, as the following discussion illustrates.

*The Importance of Case Knowledge*

Case knowledge is an important aspect of ensuring appropriate diagnosis and treatment. As indicated in the review of the literature, both the degree to which, and the way in which some medical problems present themselves in individuals with ID vary from the general population. Consequently, a clear understanding of these variances will only strengthen the health care a provider can give.
Several of the health care participants reiterated that they, along with their colleagues, had experienced some form of apprehension or uneasiness when starting out in caring for individuals with ID. This was in part attributed to a concern that they were lacking in specialty knowledge, and would therefore be insufficiently prepared to care for this population. The newly released Consensus Guidelines (Sullivan et al. 2005) were created in part to meet this need and to provide directives for general health practitioners based on the best available evidence regarding specific health needs for individuals with ID. In addition, the guidelines seek to establish a resource network available to general health care practitioners who need to seek out information related to particular etiologies.

Individuals interviewed emphasized the importance of having confidence in the clinical understanding and skills of their health care providers, and articulated that they felt it was essential to receiving good care that health care providers were well read and “up on” their particular health concern. Individuals expressed that they wanted their health care provider to demonstrate a good understanding of their particular health needs or at least show an interest in acquiring further information. Frustration over lack of knowledge was expressed when individuals felt that their health care provider lacked expertise regarding a particular health need. It should be pointed out that these were conditions unrelated to their intellectual disability. One individual who uses a wheelchair for mobility not only articulated his frustration over the lack of clinical knowledge of some health care providers, but also expressed how this lack of knowledge often seemed to translate into an apparent insensitivity in words, such as being asked to “hop up on the table” when such an action was clearly not possible. Individuals’ strong emphasis on
health care providers' clinical skill as being important was, in fact, greater than the responses of support persons and health care providers.

The Importance of Patient Knowledge

The extent to which individuals are able to recall and articulate their health history varies according to multiple factors. Their cognitive and expressive skills certainly play a role, as does the extent to which they have had an opportunity to speak on their own behalf in past situations. Some individuals indicated that they felt at times that it was a challenge to articulate symptoms in sufficient detail or to remember all the things they wanted to say to the health care provider. Some of the individuals interviewed further expressed that they were grateful and relieved to have a support person present who was able to “fill in information” as needed. Others clearly felt that they preferred to speak on their own behalf. A couple of the individuals interviewed demonstrated a remarkably detailed account of their personal health history including specific dates and events without any written information to guide their recollection.

Health care providers and support persons alike stressed the importance of support persons’ ability to have good understanding of the individuals’ history such as what medications and interventions may have been tried in the past. In addition, it was emphasized that support persons must have the ability to decipher and present evidence of those symptoms related to the issue of concern. Furthermore, all of the participant groups stressed the importance of sending a support person who is assertive enough to question decisions and recommend actions such as additional referrals or investigations.

The Importance of Communicative Knowledge
Health care providers pointed out that variability in individuals' communication styles and preferences make generalization regarding the communication techniques difficult. They also said that learning how an individual communicates is extremely important when establishing rapport so that communication could begin at the level suitable to an individual's needs. One health care provider indicated that it was important to know "how to pitch yourself" when first getting to know an individual and that cognitive and communicative abilities gave health care providers a starting point in the 'hows' of communication. It was suggested that questions and explanations could thereby be adjusted appropriately to meet the needs of the individual.

Support persons also reported that they often found health care providers who lacked communicative knowledge, largely because they were someone new or unfamiliar to the individual, would often direct both questions and explanations to support persons with the expectations that support persons would then modify the information to the level appropriate for the individual at a later time. Support persons expressed dissatisfaction with this practice as it often meant that they were placed in a situation of providing medical explanations of which they themselves might not have a full understanding. Instead, they stressed the importance for health care providers to provide explanations to individuals directly while being mindful to slow down their explanations as needed and checking back in order to ensure comprehension.

The Importance of Person Knowledge

Liachenko (1997), in expanding the concept of person knowledge, suggests that “such an understanding necessarily implies knowing how the person is situated in and engages with the world” (p.27). In the present study, all participant groups placed greatest
emphasis on issues surrounding person knowledge and the importance of 1) recognizing the individual as expert, and 2) recognizing and encouraging increased ‘person knowledge’ by support persons and health care providers. Heyman, Swain and Gillman (2004) provide the challenge to look beyond a “culturally derived, monolithic view of expertise” (p. 366), and the table suggested by Grant (see Table 4) does just that. Within the interview responses, it became clear that the most meaningful way to recognize the expertise of the other(s) was by listening to them, considering their perspective as important, and being open to learn from each other.

All persons are experts in ‘what it means to be me’ regardless of their ability or inability to articulate it in a way that others can understand easily. At home, individuals emphasized the need for support persons to listen to their concerns and take them seriously. They expressed frustration over situations in which their concerns were dismissed. In health care consultations, individuals interviewed stressed the importance of feeling that they had an adequate opportunity to address their concerns, and praised those health care providers who paid attention and showed interest. Individuals indicated that by speaking to them first, health care providers demonstrated that they felt the individuals’ report of the situation was of primary importance.

Health care providers and support persons pointed to the goal of getting to know the individual on a personal level as being imperative to their own provision of care, as well as within the expectations of each others’ role. Health care providers emphasized strongly the importance of support persons being “in tune” with the individual they were supporting and praised the efforts of those support persons who spoke clearly, not only about symptoms and medical background, but also showed a deep understanding of the
individuals' personal preferences and needs. Similarly, support persons made several references to the positive nature of health care encounters where the health care provider seemed to make a genuine effort to get to know the individual on a personal level and to truly connect.

Health care professionals' emphasis on the significance of person knowledge within the present study is in contrast to the findings of Ziviani et al. (2003) who indicated that "GPs made very few references to the interpersonal or relational nature of their discussion with people with a disability, whereas this was a primary focus of both people with an intellectual disability and their carers" (p. 6) A possible explanation of this difference in focus might be that the health care practitioners interviewed for the present study were recruited through purposeful sampling and had a recognized expertise in caring for individuals with ID whereas those recruited for the Ziviani et al study were not.

Having person knowledge also implies an increased recognition of the normality of a person's life. As Gillman, Swain and Heyman (1997) indicate, "information about the 'ordinary' life of an individual is confirming sameness rather than accentuating difference, whereas information constructed through professional discourse has a tendency to be problem saturated and pathologizing" (p. 682). One of the support persons interviewed gave me the opportunity to look at a photo book belonging to one of the individuals she supports. Essentially, it is a personalized collection of photos and mementos that serve multiple purposes. Clearly, it is an important keepsake for someone to have and look back on significant people and events in their life. People who use this kind of book can take it to hospital when they are admitted where the book serves an
additional purpose, as the following account provided by one of the support persons interviewed explains:

But what we do is, we have this photo book, and its… it’s kinda like highlights… like, real kinda big points in their lives so that…. When they’re there, sometimes, because they know they’re from a group home, they think that that’s how they always are… sick or you know, not well. But it’s not the case… they’re healthy, like you and I are… and uh, it’s just they’re in for either surgery or an emergency. Something has happened to them, so… we really bring those photo books in and, uh, the nurses go through them and they love them… So it’s just so that they could actually see that no, this is, like, they’re here cause they’re sick, it’s not… he’s not always laying here like that.

You know, he’s up and moving and about and… they’re normal…

The photo book serves to give health care providers a glimpse into the ‘ordinary life’ of an individual and thereby increases their ‘person knowledge.’ Sullivan and Heng (2005) fittingly point out the positive results of greater person knowledge:

The end of health care is not only what is medically good but what is good to this patient in relation to his or her unique life circumstances. A sympathetic knowledge of the personal circumstances of people with developmental disabilities is often essential to understanding the presenting health problems and needs and figuring out the hidden ones. A personal knowledge also enables the health care professional to help people with ID and their significant caregivers to appreciate the lifestyle changes entailed by options for prevention, treatment, or
management, and to participate in choosing the most suitable one for the individual. (p. 4)

The Proposed Addition of 'Intuitive Knowledge'

In reflecting on the responses of the participants within the present study, it also becomes evident that perhaps ‘intuitive knowledge’ should be considered as an additional part of person knowledge. This concept, discussed and refined by several authors within the nursing literature, is a recognition of subtle difficult-to-describe variations characterized by behaviour changes or changes in colour or temperature noticed through tactile or visual senses but whose “finite distinctions are limited by language” (Minick and Harvey, 2003, p. 292). Polanyi (1966) described these limits of language to convey the infinite details that the human senses can perceive while outlining the structures of tacit knowledge.

The term intuitive knowledge can be adopted in the present discussion as the ability of both support persons and health care providers to pick up on, make sense of and respond to both verbal and nonverbal signals, a skill which Benner and Wrubel (1989) describe as the essence of a caring relationship, and further to the ability to instinctively know when something is not right. Respondents in all groups alluded to this skill of “picking up on body language,” “being able to tell just by looking... something is off,” as being important for support persons to possess and emphasized that what makes such knowledge possible is continuity of care.
The Risk of Getting Stuck at Case

Case knowledge, taken alone, runs the risk of becoming what Gadamer (1975) refers to as "objective knowledge of the other" (p. 322). Arnason (1997), in his discussion of Gadamer's work, goes on to state that "this claim to objective knowledge of the other is a mode of observation rather than of interaction and communication. Though it may be medically effective, it cannot be conducive to a good professional-patient relationship" (p. 18). Gillman, Swain and Heyman (1997) describe the subjectivity and objectification of people with ID as their having "been made the 'subjects' of professional attention and theorizing (they are a 'client group'), and have become objectified as 'cases' or 'problems'" (p. 676). When decisions are made based on case knowledge alone there is an unspoken dismissal of personal agency; the personal circumstances of an individual's life are seen as irrelevant to proper treatment. In the present study there was clear disapproval expressed by support persons and individuals with ID alike when health care practitioners were seen to be making decisions based on incomplete information and before even making an attempt at securing additional levels of knowledge.

The Risk of Premature Understanding

"By understanding the other, by claiming to know him, one takes from him all justification of his own claims" (Gadamer, 1975, p. 323). Arnason (1997) refers to this inference that one understands the other better than the self as a form of benevolently paternalism. It assumes that one recognizes the other as a person but, as Arnason (1997) explains, "the professional who seductively and prematurely claims to understand seeks
to establish a different authority which may make the other more dependent on the relationship. It implies an interpretation of the needs and interests which are to be ‘for the best’ according to the needs of the professional” (p.19). Support persons who are given the great responsibility of “speaking for,” and “being a mouthpiece for” individuals run the risk of such premature understanding, a clear concern articulated by support persons themselves. There was a clear recognition that such a role was based on a great deal of trust on the part of the individual and that the responsibility of “talking for someone” must not be taken lightly.

Being known – in summary

There was strong agreement amongst individuals, support persons and health care providers alike that to strive to know someone more fully within each of the domains described would provide better support communication in health care situations. A challenge to care providers at all levels should be, therefore, to attain this goal. The prospect of achieving it increases dramatically as individuals with ID are given opportunities to make their wishes known by expressing the words articulated by individuals in the interviews.

(Interviewer) Is there anything that you wish your doctor would do differently?
A. Well. Try to understand me.

(Interviewer) Are there other things that it’s important for the doctor to do?
A. To find out. To find out the way I work.

Or as Atkinson and Williams said poignantly, “know me as I am” (1990, p. 5).
Being well supported

The impact of the contributions that support persons make to the health care status of people with ID has not been the subject of extensive research despite the fact that they play a critical role in influencing health and wellbeing (Cheetham et al., 2007; Lennox & Edwards, 2001). Lennox and Edwards suggest that past research activity has often involved information obtained “second hand” (p. 45) through managers or supervisors and speculate that considerable “re-interpretation” (p. 45) may take place where key issues are underestimated or passed over.

The Concept of Being Well Supported

An important strength of the present study is that interviews included and were carried out with support persons directly, and that their contributions to both the general health of the people they support and their role in communication within health care encounters were considered as an important part of the study. In addition, an examination of the roles and expectations that each participant group has of each other allowed a unique comparison of understandings across informant groups.

Support persons have direct daily influence on health care decisions ranging from diet and exercise opportunities to medications and treatments (Lennox and Edwards, 2001). Furthermore, vital functions of support persons include identifying if and when a health issue that needs attention, assisting in a health care medical encounter, and providing information to the health care practitioner that aids in diagnosis, as well as monitoring subsequent treatment (Cheetham et al, 2007).

According to Ford and Honnor (2000), quality services in community care for individuals with ID rely upon recruitment and retention of staff who are highly motivated
and satisfied with critical aspects of what they are employed to do. The support persons who volunteered to participate in this study demonstrated high levels of interest and commitment to the clients they supported and, in fact, participation in the study may have been influenced by such personal motivation.

Cheetham et al. (2007) describe the frustrations of a support person over having their observations ignored when trying to draw attention to an individual’s health needs during an appointment with a health care provider. This support person described the role of the support professional by saying “we are in the business of observation” (p. 630). As discussed in the previous section, the ability to take note of clear as well as subtle changes in a person’s appearance, demeanor or behaviour that may indicate changes in health status is an imperative part of the support person’s role. But clearly, as evidenced by the above description, and as echoed within the responses of the support persons interviewed in this study, their responsibility runs much deeper than observation. Despite the relatively small sample of support persons interviewed, the multiple dimensions and complexities inherent in their role was very evident. Cheetham et al (2007) reiterated that, as medical practitioners, they rely on support persons and

continue to be surprised at how apparently trivial and nonspecific observations can herald specific medical problems. In many instances, a support person’s concern that something was wrong or usual led to the discovery of an important medical problem that required treatment, when taken seriously and investigated. (p. 630)

The value of continuity of support persons has been acknowledged as an important component in the identification of health needs for individuals with ID
(Purcell, 1999). However, one study suggests that ongoing relationships can also make
some needs more difficult to spot, such as those where deterioration is gradual, as is the
case with sight or hearing loss (Kerr et al., 2003). Several studies have pointed to the
challenge experienced by support persons in identifying health needs in those they care
for, and some have suggested that “health management by proxy” (Cooper et al., 2006, p.
667) frequently means that health needs go undetected. A health care consultation should
be an active and collaborative partnership (Roter, 2000). However, as Lennox and
Edwards (2001) point out,

This task is difficult when the patient with an intellectual disability has
communication problems and they are dependent upon carers to identify and
interpret signs of illness or being unwell. The role of the medical practitioner in
diagnosing and treating in response to this filtered information is therefore made
even more difficult. (p. 26)

The results of the present study showed that all participants recognized the crucial
role that support persons can play in ensuring good health care for the people they
support but also pointed out some clear divergence in perspectives.

The Importance of Dialogue

The health care providers interviewed placed greater emphasis on information
that was brought to the encounter as opposed to that generated during it, and perhaps
understandably so, as the clarity of information that is brought to the encounter makes the
health care provider’s job of diagnosis and treatment much easier. Health care
practitioners placed great value on the insight and perception skills of support persons
and their ability to relay their observations clearly. Individuals with ID similarly relayed
that an important role for support persons is to fill in gaps in information, and to provide
details to the health care provider over and above what the individual him/herself can
relay. Support persons also recognized the pivotal role they play in ensuring the
transmission of information to the health care provider.

In addition, to a much greater extent than the other participant groups, support
persons also emphasized their role in the transfer of information from health care
providers to the individuals they support. Support persons stated that they often felt that
the health care providers left the explanation of treatment options and even of diagnosis
up to them. They reiterated that they felt they were often expected to pass along
information about which they themselves sometimes had only a partial understanding.
The most difficult of such instances were when the information involved the delivery of
bad news. One support person gave the example of a health care provider who delivered a
palliative diagnosis. The information provided by the health care provider was directed at
the support person but delivered in front of the individual, and left the support person
visibly shaken and upset. When the health care provider left the room, the onus was
placed on her not only to explain her emotional reaction to what had been said, but also to
explain the diagnosis to the individual. Support persons expressed frustration at being left
to decide what and how much information to provide to individuals and said that they
often felt ill prepared to do so. These concerns echo those of previous studies that have
looked more specifically at the role of support persons in delivering difficult information
to the individuals they support (Jones et al. 2006, Brown at al., 2002, Todd 2002).

When the responsibility for relaying information is placed in the hands of the
support person, it also takes away the opportunity for individuals to ask, and have their
questions answered, by the health care provider. As Dunn et al (2006) claim, “If we are to help people with learning disabilities play an active role in making decisions about their lives we must (a) ensure they have enough information relevant to the decision making task and (b) endeavour to present this information in an accessible form” (p. 318). The strong emphasis on the transfer of complete and accurate information in both directions by support persons highlights their role within the dialogical nature of the interaction.

**The Importance of Challenging the Plan if Needed**

It was the health care provider participants who indicated clearly the expectation that support persons must speak up and challenge the health care professional regarding concerns that they feel need to be addressed. Even if the health care professional dismisses or minimizes the concern, the health care providers interviewed emphasized the need for support persons to “stress their agenda” and “bring forward” symptoms that they feel should addressed. Such a task is not always an easy one. Support persons may feel that they are not in a position to question the impressions and recommendations of the professional health care provider who is seen as having the expertise in medical knowledge. This again points to the clear need of all parties involved to recognize the expertise in each other as well as in themselves, and to feel comfortable in voicing their unique perspectives.

**The Importance of Balancing Dual Roles**

A prominent theme underscored in the narratives of all participant groups is the complex responsibility for support persons to balance what Friedman, Helm and Marrone describe as “autonomy versus influence” (p. 355). This professional dilemma has been
given thoughtful attention in the research literature involving health care providers, but it
has been examined to a much lesser extent in relation to the similar conflict faced by
support persons for individuals with ID. In the present study, this difficult balancing act
was emphasized as a daily challenge for support persons.

Health care providers demonstrated a clear recognition of the “ongoing
negotiation” necessary for support persons to decide to what extent they should provide
assistance to the individuals they support. Such decisions were seen as situational and,
therefore, require a “constant balancing act” based on the needs of the individual at the
time and within a specific set of circumstances. However, it was the support persons
themselves who provided articulate examples of instances in which that intricate balance
proved itself to be a difficult role to navigate. In particular, support persons spoke of the
difficulty in ensuring that they were supporting the rights of the individuals to make
choices, while at the same time ensuring that the individuals received the best health care
possible. However, support persons indicated that the rights of individuals within health
care is increasingly being recognized.

It’s just basically, yeah, that they, they do have a right now, they can say no, or
they can say yes and it’s like enforcing that, but also letting them know that
sometimes you may not want to have a certain thing done, but it’s for the
betterment of their health

They also indicated that the role of convincing someone to go through with an
examination or investigation was often left up to them, and the difficult determination of
how to provide information without “overstepping their boundaries” is a difficult one:
Yeah, I also have that responsibility to say that “you really need to have this done” and most of the time if you can sit down and explain why and they do, they trust you. So it’s like once they get past it, it’s like okay, we just want to make sure that you can continue to do the things that you like to do every day and if you don’t have that x-ray done, I don’t know that there’s not something broken since you’ve fallen...

Friedman, Helm and Marrone (2000) discuss the dilemma of autonomy versus influence for professionals who care for individuals with ID. They make the premise that “it is proper and ethical and, in fact, supportive of the concept of consumer or patient autonomy for the professional to actively seek to influence the decision and actions of the persons(s) being helped” (p. 355). They provide a rationale for their suggestion based on the recognition of differences in expertise suggesting that a helping professional will have a different set of knowledge and skills than those of the person being helped. This ties back to the different levels of knowledge and expertise suggested by Liachenko (1997) and Grant (2005). Friedman, Helm and Marrone (2000) further suggest that “influencing is felt to embrace rather than reject autonomy [in] that a relationship based on equality of power and mutual relationships naturally involves each party trying to influence the other” (p. 355). However, knowing just where to draw the line between influence and control and how much is appropriate within a particular situation is extremely difficult.

One support person recalled an incident where an individual being supported had made the decision not to attend a long awaited appointment with a specialist. While the support person interviewed adamantly agreed that self advocacy skills are integral, and that the individuals supported by the agency need to have a good understanding of their
rights as individuals, he also made the suggestion that at times, the degree of influence necessary to ensure that people receive the care they require means that support persons must carefully balance advocacy, influence and control.

No, he’s going. Don’t be sitting there at meetings and saying, well if they don’t want to go then they don’t have to go, uhm, this isn’t a toenail appointment guys, uh, this stuff is pretty serious. It’s like because you go back to that whole question about their medicals and things like that, that’s why we’re here. Bottom line. You know, involve the guys as much as you possibly can in what they understand but that’s why we’re here. Sometimes we have to make decisions that aren’t always popular….But if we didn’t care we wouldn’t do it. It’s not about, it’s not a control thing… but I know how important it is, they have to go.

Situational examples such as the one above draw attention to the extremely challenging dilemmas faced by support persons in ensuring good care for those they support. It is important to emphasize that, among the individuals with ID interviewed in this study, there were those who expressed strongly that, more often than not, they choose to meet with their health care provider alone. They stated that their support person was there to assist with basic needs, such as transportation and ensuring that prescriptions were filled. However, they preferred to have the support person wait outside the room so they could meet with their primary health care provider in private. The support persons interviewed indicated that they respected and supported those decisions but also said that there were times when they felt torn because they preferred to attend the appointment to make sure that the health care provider was given all the information needed; however, they also wanted to respect the individual’s need for privacy.
Van Hooren et al. (2002), in their study examining the role of care providers for individuals with Prader-Willi syndrome (PSW), astutely point out that “the dichotomy between respecting autonomy and securing freedom of choice on the one hand, and paternalism on the other, is too crude to do justice to the process of care” and the results of the present study echo the same belief. Drawing on a model from Emanuel and Emanuel’s (2002) work on physician-patient relationship, Van Hooren extended their focus to the relationship between caregivers and care-receivers. There are parallels that can be drawn between the work of Van Hooren et al. and the results of the present study, suggesting that autonomy and dependency are not opposites. Instead, a “deliberative model” of care in which dialogue and discussion play a central role suggests a way to support individuals to determine and choose the best options for good health (Van Hooren et al., 2002).

The Risk of Underestimation

According to Beange (1996), individuals with ID have to “negotiate health care through another person which only works successfully if their agent is trained and empathetic and does not underestimate their complaints” (p. 159). Support persons must make the decision about when to access health care. The support persons interviewed in this study expressed the view that the “better safe than sorry” reasoning often weighed heavily in that decision. In addition, support persons carry the responsibility of not underestimating the individual’s right to make decisions, even if they feel those decisions are not in the individual’s best interest. Support persons interviewed emphasized the complexity that balancing these sometimes competing responsibilities entailed.
The Risk of Second Hand Information

During health care consultations support persons, in essence, have to pass information in two directions and, as such, act as a filter in what and how much information is communicated. At times, they must direct the conversation to ensure that the individual has an opportunity to voice his/her concerns. Support staff must also know if and when to add information to ensure that the health care provider has all the information necessary to make an accurate diagnosis. However, as Law et al. (2005) states, “the contributions of support persons can only ever at best be a second guess and therefore not always an accurate reflection of the service user’s perspective” (p.182).

Being Well Supported – in Summary

Support staff carry the responsibility for making that second guess as accurately as possible based on their knowledge of the individual. Furthermore, they must ensure that the information passed on from the health care provider to the individual is presented in a way that is well explained and understood, and that the individual has a chance to get clarification if needed. The diverse perspectives and views expressed in this study point to the complexity of the role support persons play.

Being well aware

Individuals need to have greater awareness of how to best support themselves in health care interactions, to ensure that they get the most out of the encounter. It is imperative that a reflection on the findings within this study conclude with a closer examination of how the participant groups looked at individual factors.
The concept of being well aware

Expressed in the views of participants there is an increased recognition of the importance of supporting autonomy and decision making within health care encounters for people with ID, yet there continues to be much room for improvement. As Solar and Irwin (2005) state, “people with intellectual disabilities are capable of assuming greater control over their lives, and they deserve the opportunity to do so and to be supported in doing so as fully and effectively as possible” (p.47). At the very centre of efforts to bring about positive change is the need to ensure that individuals gain both the opportunity and the confidence to fully participate in their health care, which restates the significance of the 3Rs project.

Being Aware of How to Overcome Fear

Anxiety and fear were mentioned as significant negative contributors towards establishing good communication and care. Support persons and health care providers alike suggested that fear on the part of an individual would sometimes result in refusal to attend appointments, as well as challenges within consultations. Most significantly, a fear of painful procedures such having blood drawn, was suggested as an important barrier. This echoes the findings in past studies which make the suggestion that fear of accessing services, fear of procedural pain and discomfort and fear of encountering negative attitudes amongst health care providers create very real barriers to effective health care. Information regarding effective communication approaches for health care providers offer positive suggestions on how to help alleviate fear and anxiety in consultations, such
as providing explanations before doing an examination, demonstrating procedures, and allowing opportunities for clarification. According to one participant,

A person with intellectual disabilities may think only about the temporary pain of a procedure, and not be able to visualize the health problem that it prevents. When a person is refusing a blood test for example, because of the immediate discomfort, it is helpful to demonstrate and emphasize that any distress is short lived.

The fear of needles was mentioned as a common example by several support persons. It is therefore also important to consider simple interventions that can reduce pain, for example the pre-administration of a topical anesthetic prior to blood work or injections, be considered as an effective way to reduce actual pain as well as lessening anxiety and fear.

While there exist some very useful easy-to-understand books created for individuals with ID which seek to increase understanding of health related topics as well as decrease apprehension and fear, many of these have not gained common use. The larger number of health care practitioners with a special interest in the field of intellectual disabilities I had an opportunity to get to know through the Guidelines training expressed a keen interest but limited experience and familiarity with resources available such as Books Beyond Words (Hollins et al., 1998-2008).

With fear sometimes playing such a significant role, it is essential that it be recognized and that greater emphasis is placed on empowering individuals to not only feel in control in the giving and receiving of information, but also to be equipped with positive coping strategies that have been shown to help relieve anxiety. Only a limited
amount of research has looked at strategies aimed at individuals themselves that teach coping skills in medical situations. Lunsky, Straiko and Armstrong (2003) provide an important model of intervention in the development of the “Women Be Healthy” program. Participants in the program showed positive changes in being able to recall and make use of coping strategies during medical procedures. The authors point out that addressing more intense fears reported by some women with ID may also require more specific individual therapy approaches. Lunsky et al. also point out the importance of staff involvement in helping participants to practice and generalize their skills.

Participants in all groups within the present study expressed that a positive way to lessen anxiety was through continuity and familiarity, a comfortable sense of knowing and being known. This applies to both support staff and health care providers who by having a greater understanding of the person knowledge of the individual would have a better understanding of what types of preparation and positive interventions would be most helpful to the individual. It is imperative that individual fears be recognized and addressed rather than being dismissed as irrational or unfounded, and an increased understanding of this important fact can assist individuals, support persons and health care providers to work towards learning new and innovative ways for fear to be overcome.

Being Aware of Self Advocacy and the Right to Make Choices

Several health care providers made the suggestion that many people with ID usually have not had the opportunity to act as active agents in health care situations and, therefore, may lack the assertiveness skills needed to articulate their needs, and act as
advocates on their own behalf. Ziviani et al (1999) had similar results in their findings and suggested the following explanation:

Many people with disabilities, especially those that have come out of institutions, have strong feelings of disempowerment. The socialization that they received in various segregated settings, e.g., institutions, special schools, etc, has made people with an intellectual disability feel powerless and devalued. In the doctor-patient encounter, they may be awed by the situation, and thus lack assertion with the doctor who is seen as an authority figure. With such feelings, these people are seen as less likely to volunteer information and more likely to accede to suggestions from an external person.” (p.2)

While many of the individuals who took part in the present study demonstrated a positive awareness of how to recognize and communicate signs of ill health, support persons and health care providers suggested that for many people with ID, this is very much a challenge. The Health Self-Advocacy initiative in the 3Rs Project is currently pilot testing a health knowledge and health rights educational program. This initiative emphasizes the need to equip people with ID with information about their health and their right to be active participants in their own health care.

While the issue of making choice was not the primary focus of this study, it became apparent through the narratives of the participants that this was recognized as an important consideration in establishing effective communication in health care settings. As discussed under the previous heading, support persons described what Ellem (2005) refers to as the “paradox of care” (p.15) in encouraging independence as well as ensuring good health and good care, where the choices made by a supported individual seemed to
be in opposition to what the support person or health care provider feels is in the individual's best interest. Sutherland (2002) states that "the relative merits of exercising control over the choices made by people with intellectual disability so they make 'good' rather than potentially unhealthy decisions is open to conjecture" (p. 440). The findings of this study reaffirm the innate challenges apparent in balancing that support. Sutherland further points out that "the right to choose and making 'good' choices should not necessarily be viewed as conflicting goals" (p. 440).

Ensuring opportunities for choice and decision making in health care settings is receiving increasing recognition as a vital function to ensure good health for individuals with ID. Interact Theater Company (2000) has created a curriculum and video that illustrate the differences between new fads or trends in providing services to individuals with ID and what individuals actually want for themselves appropriately entitled "my choice, your decision". Flynn, Keywood and Fovargue (2001) suggests when individuals are denied the opportunity to make choices whether in important clinical decisions or in more routine situations, a negative feedback loop is inevitable where being unaccustomed to making choices leads to lessened opportunities to do so.

Not being used to making decisions in the more mundane, non-invasive forms of health care leads to a situation where people do not make decisions; the fact that they do not make decisions then becomes the rationale for not consulting them. (2001, para.5)

Having information about the nature of treatment is an essential element in informed decision making, yet several participants expressed that the lack of clear and understandable information was a primary concern. Lennox and Edwards (2001) make
the suggestion that while current policy and legislation does promote the importance of quality, participation, choice and empowerment for people with disabilities, they echo Hardy (2003) and conclude that "evidence suggests that the gap between client involvement ideal and what usually happens is still considerable" (Lennox and Edwards, 2001, p. 3)

Lennox et al. (2004) have provided a practical tool, the ASK (Advocacy Skills Kit) diary and training, that aims to improve communication between health care practitioners and people with ID. The diary is intended to belong to the individual and to provide a place where pertinent health and personal information can be stored and easily shared between the individual and his/her health care practitioner. In addition, it provides health advocacy tips for individuals, as well as information for health care providers on how to enhance their primary care skills in working with people with ID. One of the many promising benefits of the ASK diary is the sense of ownership it provides to individuals and the subsequent increased sense of their control in the health care setting.

*Being Well Aware – In Summary*

Valuing People (2001) contains the following statement:

Whilst people’s lives and aspirations may differ, the starting presumption should always be of a person aspiring to independence, rather than to being encouraged to be dependent. Independence does not mean doing things unaided, but support being offered to maximize this” (p.23)

Several participants from all groups were quick to reiterate these thoughts. As one individual with ID resolutely pointed out, the decision to have a support person present during a medical consultation was his, and it was his belief that her presence
enhanced rather than detracted form the positive communicative relationship that he had with his health care provider.

In line with the notion of relational autonomy, where feminist scholars have brought attention to the social context in which people live and the interdependencies that lead to autonomous actions (MacDonald, 2002), communication between individuals with ID, their support persons and their care providers must be seen as a collaborative and deliberative enterprise which leaves room for positive influence and support while ultimately leading to “meaningful self direction” (MacDonald, 2002, p. 194). A table of the discussion themes is provided in Table 5.

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<tr>
<th>BEING WELL BEMET</th>
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Table 5 Key themes drawn from the present study.

IMPACT OF RESEARCH ON THE RESEARCHER

As Russell and Kelly (2002) point out that underlying all research projects is, among other wishes, the desire to learn something new, and researchers often simultaneously find themselves transformed throughout their research efforts” (Brydon-
Miller & Tolman, 1997). Russell and Kelly further point out that the result can be that researchers become more conscious of how they react and respond to others, and how others react and respond to them, while recognizing their own strengths and limitations. All of these outcomes rang true within this research endeavour and what follows is a reflection on how these have impacted me as researcher, student and practitioner.

At the very onset of the interview process, the development of a positive rapport was extremely important in each and every interview. The unique nature of the participant groups necessitated careful reflection on how my role as researcher was perceived by those I interviewed. Ellem (2005) talks about “crossing the communicative divide between the researcher and the research” (p.14) and I became aware of the importance of being open to finding ways in which to close the gap by tailoring my own communicative style to best suit the need of each participant. I also found it important to explicitly and forthrightly ensure that the participants in the study had a clear understanding of the purpose of the interview and that there was no underlying agenda of checking up on participants’ knowledge, abilities, or practices. This was especially important in the interviews with support persons.

I found that the process of communicating in order to gain a greater understanding about the individuals I interviewed was, as Thorne (2000) suggests, at first a familiar and comfortable task. “After all, nurses have always based their clinical practice on learning as much as possible about the people they work with, and detecting commonalities and variations among and between them in order to provide individualized care” (Thorne, 2000, p. 68). However, I learned important lessons about the impact of communication in how the interviews played out in practical terms. Clinical interviews and qualitative
research interviews share some common qualities but have very different purposes (Britten, 2006). Ultimately, a clinician will seek out information aimed at gaining a complete understanding of an individual’s circumstances in order to plan out personalized treatment and care. In a qualitative interview, the goal is to “discover the interviewee’s own framework of meanings and the research task is to avoid imposing the researcher’s structures and assumptions on the interviewee’s accounts as far as possible” (Britten, 2006, p. 14).

Thorne (2000) goes on to describe that simply gathering and reporting data is insufficient for a qualitative research study, and that “a qualitative researcher must engage in active and demanding analytical process throughout all phases of the research” (p.68). Sandelowski and Barroso (2003) further challenge researchers to “take a risk and commit to making an interpretation in the data analysis process” (p.913). Taking this risk was a daunting task from the point of view of a novice researcher and I wanted to amplify the voices of the participants without falling into the trap that Atkinson (1997) refers to as “romanticizing” the accounts of the interview participants.

Thorne and Darbyshire (2005), with tongue firmly planted in cheek, speak of “cardiac validity,” how heartfelt are the interpretations, or “lachrymal validity,” how deeply moved and lead to tears is your intended audience? (p. 1110). It was my goal to adhere to a method of analysis that was thoughtful and systematic and that provided a clear record of how I arrived at my conclusions. To the extent that they fail in their analytic endeavours researchers demonstrate what Barbour (2001) calls “near mysticism [wherein] a slight of hand produces a list of themes.” (p.1116) Thorne (2000) makes the lighthearted suggestion that it is “almost as if they had left the raw data out overnight and
awoke to find that the data analysis fairies had organized the data into a coherent new structure that explained everything!” (p. 68). Barbour (2001) further warns against producing an “artificially neat and tidy account” (p. 1116) and while I have framed the themes in a way that may leave me wide open to such criticism I have also learned the importance of, and have demonstrated a clear chain of evidence that supports my interpretations.

Lennox and Eastgate (2004) stressed the need for health care providers to “listen with all their senses” (p. 603). While they were referring to a clinical interview, I believe strongly such advice can be applied within the research setting as well. In the course of this study I found that while I had the verbatim interview transcripts at hand, it was oftentimes more effective to go back to the audio taped versions of the interviews to get a fuller understanding of how things were said along with what was said. On a more meaningful level, the very act of becoming more skilled in listening in an active and reflective manner that necessitated ongoing paraphrasing of the message being sent to ensure it was interpreted correctly, has impacted how I reflect on the universal struggle to understand and to feel understood.

STUDY LIMITATIONS

The 14 participants in this study provided extremely information-rich data. However, they cannot be said to represent the entirety of perspectives within the group which they represent, and thus the findings cannot be said to be generalizable. The data were derived from a single interview conducted with each participant due to resource limitations. While a rigorous research process was adhered to, repeated interviews with
each participant would have provided the opportunity for more detailed exploration of themes. In addition, an opportunity to observe an actual health care encounter with representatives from each participant group may have lead to a greater understanding of the participants’ lived experiences. Heyman et al. (2004) make the suggestion that a “narrative research approach may accentuate the reporting of negative anecdotes which provide good stories” (p.365) and while it is important to keep such notions in mind, it is equally important to not dismiss or undervalue experiences based on such speculation.

The sampling strategy of asking for volunteer participants who were open to take part in a verbal interview resulted in the exclusion from this study of individuals with greater communication difficulties, including those with severe and profound ID. Their experiences were reported only indirectly by the other participants. It is imperative to point out that the health care challenges of people with more extensive communication difficulties may be comparatively greater than those who were interviewed in this study. As lacono and Johnson (2004) point out “a common mistake is equating communication with the ability to speak” (p. 587). It is therefore strongly emphasized that additional research should include those with more complex communication needs.

In addition, the individuals who took part had all participated in the 3Rs Human Rights Training program through their agency before being interviewed for the proposed study. Through this training they have actively engaged in a program designed to give people with ID the opportunity to learn about their human rights and to explore the concepts of rights, respect and responsibility (Owen et al., 2002). The possibility that their past 3Rs training may have influenced how they expressed their thoughts and views
on topics related to rights and empowerment is one which must not be discounted and may have facilitated discussion of rights-related topics in the present study.

The health care providers who took part had a recognized interest and expertise in the area of intellectual disabilities and were therefore quite probably more sensitive and responsive to the aims of the project than if a random sample of health care providers had been interviewed. However, engaging those who can be described as “thoughtful clinicians” McPherson and Thorne’s (2006, p. 9), who have a recognized knowledge and expertise based on both interest and experience, can be seen as a positive contribution since the purpose of the study was to tap into the experiences of the participants and to seek out what works best in supporting and maximizing communication.

The support staff who participated in this study were all employed by one community agency. Had time and resources allowed it would have been useful to broaden the recruitment base to include those from a broader range of community organizations. This would have allowed for an investigation of whether themes arising from this group were universal or were in some way specific to one organization.

Given the small sample size in each group of this study the analysis reflects only an analysis of the experiences of these individuals and cannot be said to be necessarily representative. However, as mentioned earlier, it is interesting to note the similarities in the thematic findings of this study with other similar investigations.

RECOMMENDATIONS FOR FUTURE RESEARCH

A strong theme that, while not the focus of the present study, nevertheless emerged as an important consideration was the issue of choice. Future studies should be considered that address this concept to a greater degree. The triangulation of perspectives
in the present study strengthened the understanding of perceived barriers to health care access as well as what helps and what hinders communication in health care encounters. A similarly multi-perspectived exploration of how each group of participants view the process of making choices and their role within it would provide an important supplemental understanding of the complexity of the concept of choice in health care encounters.

Furthermore, a narrative analysis of recorded health care encounters in which an individual with ID, a support person and a health care provider are engaged in dialogue would give a different account of the experience and provide an opportunity for a more in-depth analysis of the relationships and roles at play. Such an undertaking was beyond the scope of the present study but would provide an important viewpoint in understanding of how the interaction is shaped over time.

One of the participant groups in this study was support persons. In this case this group consisted of paid group home staff employed in a community agency. A key support group that was missing in the current study was family members who may be in the position of supporting people in medical interventions situations. Inclusion of this group in future studies would allow for investigation of the perspectives of the full range of typical formal and informal health care supports available to people with ID. The unique role of family members includes their life long involvement with their family member who has ID and their particular perspective as people who may have some authority as substitute health care decision makers. In the present study, the issue of who invokes substitute decision making privileges and under what circumstance was raised and merits further investigation.
A key issue in exploring all these perspectives is the examination of each partner in the directly shared health care experience. To facilitate in-depth shared experiences it would be necessary to involve intact health care teams including people with intellectual disabilities, their primary and specialist health care providers, their support staff and their family members who support them in health care encounters. By examining interacting health care systems that support an individual it would be possible to compare members’ perspectives on specific shared experiences. While there are many practical limitations to such a study, not the least of which is the heavy time demands on the time of primary care physicians, this kind of detailed comparative analysis would provide insight into the dynamics of shared interaction and how they relate to the kind of “authenticity” in health care interactions that Arnason (1994) discusses.

SUMMARY OF FINDINGS

The present study set out to illuminate, through a multi-perspectived approach, the barriers found in accessing health care for individuals with ID as well as those key areas that participants felt weakened or strengthened communication in health care encounters. The participants in this study provided richness in data that allowed for a careful analysis of key themes. These results echo findings from previous studies that highlight that communication is central to effective health care. In order to maximize effective communication, individuals must be approached in a way that recognizes their right to be fully active participants in their health care as is the right of anyone in the general population. This includes feeling that those who are involved in their care are seeking to have an understanding and knowledge of them as unique and valued persons.
that they are supported in a constructive and affirmative way, and that they are given every opportunity to express their preferences and wishes in health care encounters.
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DATE: February 9, 2007

FROM: Linda Rose-Krasnor, Chair
Research Ethics Board (REB)

TO: Frances Owen, Child and Youth Studies
Kajsa KLASSEN

FILE: 06-094 KLASSEN

TITLE: Supporting and Maximizing Communication between Persons with Intellectual Disabilities and Health Care Providers

The Brock University Research Ethics Board has reviewed the above research proposal.

DECISION: Accepted as clarified.

NOTE: Please make sure the REB clearance statement and file number are included on the invitation letters.

This project has received ethics clearance for the period of February 9, 2007 to May 31, 2007 subject to full REB ratification at the Research Ethics Board's next scheduled meeting. The clearance period may be extended upon request. The study may now proceed.

Please note that the Research Ethics Board (REB) requires that you adhere to the protocol as last reviewed and cleared by the REB. During the course of research no deviations from, or changes to, the protocol, recruitment, or consent form may be initiated without prior written clearance from the REB. The Board must provide clearance for any modifications before they can be implemented. If you wish to modify your research project, please refer to http://www.brocku.ca/researchservices/forms to complete the appropriate form Revision or Modification to an Ongoing Application.

Adverse or unexpected events must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants and the continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocols.

The Tri-Council Policy Statement requires that ongoing research be monitored. A Final Report is required for all projects upon completion of the project. Researchers with
projects lasting more than one year are required to submit a Continuing Review Report annually. The Office of Research Services will contact you when this form *Continuing Review/Final Report* is required.

Please quote your REB file number on all future correspondence.

LRK/bb

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STUDIES EXAMINING COMMUNICATION BETWEEN PEOPLE WITH INTELLECTUAL DISABILITIES IN HEALTH CARE INTERACTIONS

**Bollard (2003) UK**

**Purpose:** To explore the experience of people with Down's syndrome when going to the doctor's.

**Methodology:** Face to face interviews with GPs and carers were carried out followed by a focus group that focused on the experience of the people themselves. The research was qualitative and sought to assess the experience and feelings that people with learning disabilities have in accessing primary and mainstream health services. The research examined how the GP derives information from people with learning disabilities during the appointment process, from the perspective of the individual.

**Key Findings:** A number of themes were elicited from the study;
- Carers require support in regard to when it is necessary to seek medical advice.
- People who are vulnerable, and can be perceived as having limited communication skills are sometimes not allowed to exert influence during the consultation process.
- Integral to the pursuit of good primary care for people with learning disabilities is the level and reliability of information given to the GP, which can assist a screening and appointment process.

**Cassidy, Martin, Martin and Roy (2002)**

**Purpose:** Health checks were offered for people with learning disabilities to detect, quantify and treat physical and mental health conditions. The study also aimed to ascertain the frequency with which the participants consulted with different members of the health care team. The third aim was to ascertain and review the medication prescribed. In addition, the researchers sought to gauge the levels of satisfaction within the patient group and of their carers.

**Methodology:** The latter part of the inquiry consisted of asking the question if the participants had liked seeing the doctor and what, if any, were their areas of concern in the consultation. They interviewed people immediately following their health check.

**Key Findings:** They concluded that:
- "low expectations on the part of the patient and carer(s),
- the burden of caring,
- the lack of provision of adequate social and health care," (p. 132)
all serve to increase the health risk in this group of people.
DHSSPS (2002)

Purpose: To discuss topics including health and access to services

Methodology: A series of focus groups were held by the department of health in Northern Ireland with people with learning disabilities. These views were presented within the "We have a dream" report prepared for the Equal Lives review.

Key Findings: The findings of this research reported that
- what happens when people with learning disabilities go to health services is compounded by previous negative experience during earlier contact
- some people with a learning disability expressed fear due in part to uncertainty about hospitals and health care professionals.
- The most important thing was that the nurses and doctors took time to listen to people. When this happened people thought they were being treated well.
  "People told us over and over that they do not like it when doctors talk about them rather than to them. If parents and staff were there, the doctors and nurses sometimes just ignore the person with the learning disability as if they were invisible." (DHSSPS, 2002, p. 21)

Hand (1999)

New Zealand

Purpose: part of a large scale New Zealand study of the entire national population aged 50 years and older with mental retardation undertaken between 1989 and 1991.

Methodology:

Key Findings:
- clinicians may need to communicated verbally and pictorially or by mime in order to help patients with ID make informed decisions about, for example, antibiotics, contraception, annual influenza shots and use of sleeping pills; or in discussing health risks such as smoking; or in promoting a healthier lifestyle.
- Listening to people with ID describe how their routinely prescribed medication makes them feel, and their everyday pleasures and difficulties helps clinicians make accurate diagnoses and improves management and treatment.
- Listening and building relationships attunes the physician to the individual's needs and makes for better observation and judgment when health problems do arise.
- Lifestyle related illnesses and disease of people with ID can be reduced by strengthening their ability to make healthy choices and to advocate on their own behalf.

Heyman, Swain and Gillman (2004) UK

Purpose: Its main aim was to explore the health needs of, and service provisions for, adults with ID, from the perspectives of service users, family carers and health and social service professionals.

Methodology: A qualitative approach to data collection and analysis was adopted. Two focus group discussions were held with adults with ID. A third focus group discussion with seven care staff from a local respite unit explored health care provision for people with ID. Participants included team managers, social workers and direct care staff.

Key Findings:
Emergent themes "what makes things worse" and "what makes things better" were explored in subsequent data collection.

Simplifying strategies observed in the study included:
- treating clients as if they possessed standard attributes,
- excluding them, overtly or covertly, from access to services
- and integrating specific health needs into a wider categorization of a condition deemed untreatable. (diagnostic overshadowing)

Iacono, Davis, Humphreys and Chandler (2003)

Purpose: To investigate GPs and support people about their concerns and priorities for meeting the health care needs of people with developmental disabilities. (Australia)
Methodology: Large scale surveys of GPs and support people
Key Findings: GPs had frequent concerns about obtaining a complete case history, conducting screening tests (e.g. pap smears), and ensuring that their patients with ID understood their instructions. They tended to rely on support people.
SP's reported concerns about health care providers of knowledge of and attitudes toward developmental disability and overlooking patients signs and symptoms of medical conditions.

Law (2005)

Purpose: To examine communicative access and participation among service users with different communication difficulties and their support persons (UK)
Methodology: This study was part of a project funded by the Department of Health in the UK entitled 'Having a Say' in which the participants were individuals with communication difficulties and a third of their sample were individuals with learning disabilities. In addition, they interviewed 'carers' of individuals with communication difficulties (referring to partner, parent or other relative or paid care staff)
Key Findings:
Law found three core themes underpinning communication in primary care;
• Inclusion - all interviewees spoke about the degree to which they felt involved in the consultation
• The process of communication - the need for the practitioner and patient to come to an agreement about the message conveyed and the outcome required.
• Continuity - the relative stability of the individuals health is dependent on a number of relationships. Shared knowledge and past experience can support effective communication.

Martin, Roy, Wells and Lewis (1997) (UK)

Purpose: The aim of the study was to identify the experiences, expectations and opinions of the people using primary health care services.
Methodology: The study was part of the Primary Health Care Project For People with Intellectual Disability in Birmingham, UK. Questionnaires followed by focus groups of 20 adults with ID, 20 carers or support people and 20 'professionals' from various professions (GPs, Psychiatrists and Social Service)
Key Findings:

- A range of communication methods is needed to assist people with ID to access their GP and understand (where possible) the constructs behind healthcare.
- In order for these to be effective and equitable, these communication strategies require sensitivity toward ethnicity, gender and cultural needs.
- Individuals need to know as far as possible what to expect from a consultation with their GP. This is as likely to help the primary health care team as it will the service user.
- The process required ongoing consultation and collaboration.
- In general, people with ID and their caregivers were satisfied with care given, but had concerns about rudeness, inaccessibility, and lack of information/knowledge about GP.
- Caregivers also reported that GPs didn't know about other services and didn't provide enough information about medications

Murphy (2006)

- **Purpose:** Objective was to explore consultation between people with communication disability and GPs from the perspectives of both patients and staff. The research sought to answer the question "What enhances understanding and what makes it more difficult?"  
- **Methodology:** Design of the study was focus groups. Eight in total were held. Four with GP Practices, two with people who had intellectual disability and two with people who had had a stroke.  
- **Key Findings:**
  - GP's expressed frustration with not being understood and not understanding but there was a lack of awareness of the reasons behind these difficulties. They all said they mainly relied on carers. They recognized the significance of poor communication in terms of access to health services and agreed that the extent of the problem was greater than they had previously believed.
  - People with communication disability described significant problems before, during and after the consultation. Although some acknowledged that they needed help from their support person, most objected to staff speaking to the support person and not to them directly. For those whose carer went with them, they preferred the carer to be a 'second pair of ears' rather than take over the consultation.
  - Continuity was found to be crucial.
  - GP's, when prompted to propose solutions to the problems, the main suggestion was 'to rely on carers', not only to make appointments, but also to speak for the client and to carry out any instructions following the consultation. Other suggestions were made such as getting to know the patient better, making a double appointment to give them more time and watching the patient for non-verbal clues.

McConkey and Truesdale (2000) (UK)

- **Purpose:** The research looked at the reactions of nurses and therapists in mainstream health services to contact with people who have learning disabilities.
Methodology: A self completion questionnaire aimed to explore the past contacts which nurses and therapists in mainstream health services have had with people who have learning disabilities and to determine their willingness for future contacts.

Key Findings:
- Less than one third of respondents answered 'definitely yes' to the items "know what to say" and "feel confident" in their interactions.
- Suggestions are made for future research that focuses on increasing the expertise and confidence of nurses and therapists in working with patients who have learning disabilities.
- Building confidence would come from selected supervised placements alongside suitable training opportunities that allow participants to explore their attitudes and values. However, if the personnel working there are themselves not confident, the risk is that these attitudes will be passed on to students. Hence the importance of providing training and support to existing staff in NHS services so that this cycle can be broken. Department of Health Guidance (NHS Executive 1998, p. 24) suggests that "this can be achieved by the use of occupational standards which are grounded in a rights-based view of service user need".
- The authors' address the fact that they assessed what respondents said they would do rather than their actual behaviours with people who have learning disabilities.

Powrie (2003) (UK)

Purpose:
Methodology: A survey of all practice nurses employed by a board.

Key Findings:
- Some nurses expressed fear and difficulty in communicating with people with learning disabilities.
- Participants indicated that nurses want better training about disabilities.
- Nurses want more effective communication and cooperation between support persons/caregivers and health care providers that they feel would improve health care for people with ID.
- Places to provide care should be extended because so many people living at home/ with families are isolated.
- Results of the interviews constituted "a plea for clarity about the rights and responsibilities of health professionals as well as the rights of people with learning disabilities within primary care" (Powrie, 2003, p. 418)

Reichard & Turnbull (2004) (US)

Purpose: To examine the degree to which the four criteria for health care (availability, accessibility, appropriateness and affordability) outlined in the Surgeon Generals Report (2002) on the health-care system and persons with mental retardation are met within the state of Kansas.

Methodology: The investigators surveyed three groups - parents of children and adults with ID, case managers for adults with ID and physicians.

Key Findings:
13% of physicians reported being generally uncomfortable working with people with ID. Barriers identified included insufficient time, and insufficient follow up with community coordinators.

**Ziviani (2004) (Australia)**

**Purpose:** The aim was to better understand the factors that have an impact upon the success of communication in a medical consultation.

**Methodology:** used interviews with GPs, people with disabilities, paid workers and parents.

**Key Findings:**

Findings suggested that:

- GPs were concerned with the aspects of communication difficulties that influenced their ability to adequately diagnose, manage and inform patients.
- People with ID reported frustration when they felt that they could not communicate adequately with the GP and annoyance when they were not included in the communication exchange.
- Carers were strong advocates for the person with ID but indicated insufficient skill and knowledge to provide the level of assistance required in the consultation.

**The Treat Me Right** report from Mencap chronicles tragic stories from a selection of people with a learning disability about what happened to them as they attempted to access health care and receive appropriate treatment. (Mencap, 2004).
APPENDIX C

Focus Group/Interview Questions: Support Staff

Semi structured interview schedule

General Introductory Questions:

How would you describe the health care of the people you support? How is this different for people who do not have ID?

What are the best aspects of the health care experienced by the people you support? How is this different for people who do not have ID?

What are your greatest concerns about the health care of the people you support? How is this different for people who do not have ID?

How does health care for the people your agency supports impact your job as a manager/supervisor?

Systemic Focus

General: Looking at how health care is provided to the people you support, how do you feel that the system of accessing health care works? How could it be improved?

- Do the people you support have, in your view, opportunities to take part in health promotion programs such as exercise or smoking cessation programs (are they offered through the association? public health? community agencies?)

- In seeking out primary care...
- Are there any challenges in finding a family doctor?
- How is it decided which doctor to access?

- Are there scheduled health screenings or checkups for the people you support?

- Who decides whether a problem is really medical?

- In a situation where medical attention is needed, who makes the decision what level of care to access (stay home versus family doctor versus emergency)?

- Are there any staffing issues when an individual needs to be taken to the doctor?

- How would you describe coordination of different levels of health care? Care coordination?
• Are there issues in making an appointment?

• Is there adequate time during a clinic visit or doctors appointment to address the needs of the individual?

• How are medical care decisions made in an emergency? when given a choice between surgery or medication for an ongoing illness?

• Describe an ideal role for staff in supporting the health care of the people in your agency/association. Can staff in your agency/association play this role? Why?

Environmental

General: Are there any physical barriers that you encounter when accessing health care for people you support?

• Are there any concerns regarding transportation to appointments/ medical care?

• Are clinics/ offices readily accessible to the people you support? (physical space)

Health Care Providers

General: Please describe your typical experience when interacting with Health Care Providers who care for the people you support. Can you tell me about a typical interaction you would have with a doctor/nurse/pharmacist [family doctor/emergency room doctor/specialist/dentist]?

• In your experience, do the health care providers you’ve had contact with have adequate training and knowledge to care for the people you support?

• In your experience, what are the attitudes of health care providers toward the people you support? (+ve, -ve examples?)

Support Person

General: What is the role of support staff [group home staff] in health care access for the people you support? Who takes responsibility for the health care of the people you support?

• Tell me about who individuals usually tell their health concerns to?

• How is it decided who accompanies an individual to a clinic or doctors appointment?

• How do staff prepare themselves and the people they support for medical appointments?
Experience of the Individual

General: How do you think people supported by your agency would describe what it is like for them to go to the doctor/dentist for a regular checkup? for a health concern (feeling sick, having a specialized test)?

- Can you describe a situation in which a person you support had a good experience? a bad experience?
- What are the main things/factors that separate good and bad experiences for people you support?

Communication

General: Tell me about your experience in communicating with health care providers within your role at the association. Can you give me an example of good communication? Bad communication? What are the key differences between good and bad communication with doctors/dentists/nurses?

- What is brought along to appointments in the way of written communication?
- (is this seen as being useful and effective or would you like to see any changes made?)
- Have you had the role of taking someone to the doctor? (if so, how do you see your role in bringing someone to the appointment)
- How involved are you in the exchange?
- Are the questions of the health care professional directed at you or at the individual?
- Who answers the health care professional’s questions?
- What expectations do you think the doctor has of you?
- What expectations does the person you support have of you?
- Who decides whether a person you support needs to have a doctor’s visit
Focus Group: People with Intellectual Disabilities

Semi Structured Interview Schedule:

General Introductory Questions:

Tell me what the best doctor in the world would be like.

<table>
<thead>
<tr>
<th>Systemic Focus</th>
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<tbody>
<tr>
<td>• What kinds of things do you do stay healthy?</td>
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<td>• Do you take part in any programs or classes that help you stay healthy?</td>
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<td>• If you wanted to take part in programs to help you stay healthy could you?</td>
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<tr>
<td>• How often do you see the doctor? Do you see the doctor for regular checkups or only when you are not feeling well?</td>
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<td>• Who decides which doctor you see?</td>
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<tr>
<th>Environmental</th>
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<tr>
<td>• Is it easy or difficult to get to your doctor’s office/clinic? (what makes it that way?)</td>
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<td>• Is it easy or difficult to get around inside your doctors office/clinic?</td>
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<tr>
<th>Health Care Provider</th>
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<tr>
<td>• What is it like to go to the doctor?</td>
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<tr>
<td>• Do you like to go to the doctor?</td>
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<tr>
<td>• What is the best thing about going to the doctor?</td>
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<tr>
<td>• What is the worst thing about going to the doctor?</td>
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<tr>
<td>• What do you wish your doctor would do differently?</td>
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**Support Person**

- Does anyone go with you when you go to your doctor’s office/ clinic?
- Who decides who goes with you to the doctor’s office?
- Is there anything you have to do to get ready to go the doctor’s office?

**Communication**

- If you have a question about your health who would you ask?
- If you are feeling sick or unwell who do you talk to?
- Do you feel that staff take your concerns seriously when you express them?
- (What do staff do when you tell them you are feeling sick?)
- When you go to the doctor’s office.
- Do you bring anything with you (papers or information?)
- What does the person who comes with you do? Do they come into the room with you or wait outside?
- Does the doctor ask you or the person you brought with you questions?
- Is it easy or hard to talk to your doctor? What makes it that way?
- Do you feel that the doctor listens to you?
- How easy is it to understand the things the doctor tells you? (For example – what medications are for?)
- If you were choosing a new doctor, what things are important to you?
- Is there anything else that you think needs to happen to ensure that when you go to the doctor, he or she will understand what you need and help you in the best way?
**Focus Group/Interview Schedule: Health Care Providers**

**General Introductory Questions:**

Could you tell me about your experience in providing health care for people with intellectual disabilities?

Are there differences in caring for people with ID as compared to the general population?

When you think about your most rewarding and successful experience working with people who have ID, what factors contributed to this success?

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<tr>
<td><strong>General:</strong> <strong>Looking at how health care is provided to people with ID, how do you feel that the system of accessing health care by people with ID works? How could it be improved?</strong></td>
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<td>• What systemic or pragmatic barriers do you experience in working with people who have ID?</td>
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<td>• Do you have concerns regarding time available for a consultation for people with ID?</td>
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<tr>
<td>• Do you see individuals with ID for general health screening/ checkups and are they more often, less often or the same as the general population?</td>
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<tr>
<td>• How would you describe the coordination of different levels of health care for this population. Are there any challenges/ gaps that you have identified?</td>
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<th>Environmental</th>
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<tr>
<td><strong>General:</strong> <strong>Are there any physical challenges in providing care to individuals who may have mobility issues?</strong></td>
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<th>Health Care Provider</th>
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<tr>
<td>• How important is continuity of health care practitioner for people with ID? Is it realistic/ feasible to expect this?</td>
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<tr>
<td>• What advice would you give to new physicians who will be working with people who have ID?</td>
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<tr>
<td>• Do you feel that medical students receive adequate training in the field of intellectual disabilities?</td>
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### Support Person

**General:** Please comment on the role that you feel group home staff have in ensuring adequate health care for individuals with ID that you come in contact with.

- Do most people with ID that you see have someone accompanying them?
- How do you view this accompanying person’s role?
- Do you find it necessary to rely on care providers for history and background information? To what extent?
- What advice would you give to support staff in preparing for a clinic visit?

### Individual

**General:** Do people with ID have health care needs that are different than those of the general population?

- What are some tools/strategies or insights that you might utilize to collect the necessary information in a situation where communication is a challenge (the individual has difficulty articulating symptoms or needs?)

### Communication

**General:** Do you find that you communicate with your patients who have ID in the same way or differently from the way in which you communicate with your other patients? If different, in what ways?

- What communication strategies do you find are most effective?
- What are the most significant communication barriers you face in working with patients who have ID?
- What methods of communication do you find most effective?
- What kind of written communication do you use with group home or care staff?
- Do you feel it needs to be improved upon? (value of health passport/journal/Diary)