EXPERIENCES OF YOUNG ADULTS WITH INTELLECTUAL DISABILITIES IN SMALL TOWN AND RURAL ONTARIO

by

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Abstract

The aim of this thesis is to analyze social inclusion among young adults with intellectual disabilities in small towns and rural community settings. The specific context is three small towns in south eastern Ontario in 2006/2007. A phenomenological study relying on a hermeneutics cycle is undertaken to derive an understanding from multiple sources.

In the first instance, policy documents related to the province's approach to supports for adults with intellectual disabilities, the research literature on experiences of adults with intellectual disabilities in rural communities, and conceptual models of social inclusion were reviewed. Seventeen young adults with intellectual disabilities (20 to 28 years of age), their caregivers (n=13) and other community members (n=20) from the three selected towns were interviewed. The interviews included quantitative tools and open-ended questions. Data from the Canadian census were also used to characterize the towns. The data collected led to quantitative (counts, median scores, proportions) and qualitative (significant statements, formulated meanings, themes) analyses for comparisons within and across towns in order to reveal the role of context in social inclusion.

The results highlight the importance of context. While similarities exist among the small towns in the region, they each have unique features which impact on the experience of social inclusion for young adults with intellectual disabilities. Key lessons are learned. Attention needs to be given to the availability and proximity of spaces and structures for interaction. The role played by developmental service agencies needs to be examined critically as it may hinder social inclusion and sense of belonging.
As community involvement is easier for those seen as similar and sense of community is stronger among those who see themselves as similar, the socio-demographic profile of a town can be an important factor mitigating for or against social inclusion efforts. Finally, since residents of a small town who have a greater need for supports derive more sense of community from knowing that other residents are willing to help those in need, fostering caring communities may be as important as creating services specific to persons with intellectual disabilities. The need for geographers, epidemiologists and other social and life scientists to study persons with intellectual disabilities within the places where they live remains a research area where there is still much to learn and be done.
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This thesis evolved from the work of the Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID; www.seocura.org) which was supported through a grant I received from the Social Sciences and Humanities Research Council of Canada (SSHRC) [#833-20003-1008]. The views expressed in this paper are not necessarily the views of all SEO CURA in ID partners, researchers, collaborators or of SSHRC.
Statement of Originality

I hereby certify that all of the work described within this thesis is the original work of the author. Any published (or unpublished) ideas and/or techniques from the work of others are fully acknowledged in accordance with the standard referencing practices.

(Hélène Ouellette-Kuntz)

(June, 2012)
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Chapter 1: Introduction

“It Takes a Village…where All People Belong”.¹

The aim of this thesis is to explore what it takes in a small town or rural community for young adults with intellectual disabilities to be socially included. The transition from childhood/school to adulthood/community life after school is a period during which an individual is redefined as a member of a community. Life after high school typically involves a move from the family home to a different neighbourhood or community concurrent with a shift from reliance on one’s family to increased independence and reliance on other social networks. For young adults with intellectual disabilities, this transition tends to be very different; few go on to post-secondary education or work, and they are more likely to continue to live with their families thereby remaining in their community which most of their age peers may have left. Their experience of community will depend largely on the social, recreational and vocational opportunities provided by their families or formally organized by their local community. But what is meant by community?

Community is an understandable dream, expressing a desire for selves that are transparent to one another, relationships of mutual identification, social closeness and comfort. The dream is understandable, but politically problematic, I argue, because those motivated by it will tend to suppress differences among themselves or implicitly to exclude from their political groups persons with whom they do not identify. (Young 1990: 300)

This thesis explores the dilemma expressed by Young through a phenomenological study of the experience of community² by young adults with intellectual disabilities in the context of rurality. The purpose of this phenomenological study was to develop a deep understanding of the


²the extent of social inclusion/exclusion measured through the construct of belonging
lifeworlds of young adults with intellectual disabilities in rural and small town Ontario. As the particularities of places (people, meanings, practices, spaces and structures) are expected to influence how social inclusion and sense of belonging are experienced, considering specific towns as cases to be studied shifts the focus from individual factors to community-level factors.

The central question of the study is “What is it like to be a young adult with an intellectual disability living in a small town in Ontario at the start of the 21st century? This question is further examined by asking the following sub-question: “How do these young adults’ perspectives on sense of community differ from that of their caregivers (parents and support workers) and other community members?” The results are further examined by asking: "What is the impact of context on sense of community among the young adults with intellectual disabilities?

While bracketing is an important element of phenomenology, van Manen (1990) points out that in an interpretive approach it is impossible for the researcher to become separated from the text. In this next section, I therefore reflect on past experiences and motivators for undertaking this study.

I grew up in a small town and I left as a teenager to pursue my studies as did many of my friends. A few returned after 4 to 6 years away but most found employment in larger centres. None of my four siblings currently live in the town where we grew up even though my parents never left it. While I value my rural upbringing and wish I could offer the benefits to my children, I have decided to live in an urban center for the employment opportunities, amenities, and cultural activities it offers. Living in a small town as an adult would seem limiting to me.

As an academic, I have worked in the field of intellectual disabilities for over 20 years and have come to understand the many challenges of living with an intellectual disability. At the time of starting this thesis, I directed a community-university research alliance concerned with
enhancing the social inclusion of individuals with intellectual disabilities. One of our research projects examined the experiences of young adults as they prepare to leave school, another focused on employment opportunities for adults with intellectual disabilities and yet another explored attitudes towards intellectual disabilities. While our region is largely rural, our research data disproportionately reflects urban realities. Despite the enhanced employment opportunities, amenities and cultural opportunities that I associate with urban living, persons with intellectual disabilities face many barriers to social participation even in urban centers.

As I reflected on my journey from a teenager leaving a small town in northern Ontario to study and then take up a faculty position in an urban University center, it occurred to me that one challenge for individuals with intellectual disabilities which I knew little about was how the transition to adulthood occurs when one lives in a rural community or small town. How does one feel? What does one want/seek? What opportunities exist? How is one perceived? Are there advantages to be found in rural living for young adults with intellectual disabilities? And, most importantly, how does the community itself impact on these other questions?

In the remainder of this introductory chapter, a reflection on policy situates the study in Ontario, Canada. Previous research on the impact of social inclusion policy is reviewed, leading to a discussion of notions of community and social inclusion.
Intellectual Disabilities, Public Policy and Inclusion

Intellectual disabilities (ID), often called developmental disabilities/handicap or mental retardation/handicap, result from a variety of insults to mental growth and development during the formative years. It is estimated that one to three percent of Canadians have an intellectual disability. (Luckasson et al., 2002; Bradley, Thompson & Bryson, 2002; Ouellette-Kuntz & Paquette, 2001; Ministry of Health and Welfare Canada, 1988) Many individuals affected will need lifelong support from family and organizations in health, education and social services.

Public policy about how best to provide support to this population has shifted dramatically since World War II. We have moved from a reliance on institutions to a preference for integration in the community. Parents, advocacy groups and the introduction of normalization, followed by social role valorization, were instrumental in the redesign of service models. The philosophy of normalization first proposed by Nirje (1970) emphasized the importance of a normal pattern of routines "to counteract the devalued ways in which society tended to think and act in relation to people with significant and obvious impairments". (Neufeld, 2001: 84) By the 1980s, the philosophy's focus on "normality" had led to misinterpretation of its intent; it was interpreted by some as aiming to make normal or to ignore specific needs. To clarify the intent, Wolfensberger, a proponent of Nirje's normalization, then advanced the concept of “valued social roles”. (Wolfensberger, 1983; Wolfensberger, 2000) These philosophies, operationalized as policy across Canada in the 1980s, (Ministry of Community and Social Services, 1987) stipulate that an individual with a disability is entitled to have as normal a life as possible through the creation, support and defence of valued social roles. In practice, this should translate into having the same opportunities for respected social roles as non-disabled members of society.
The policy shift was apparent in Ontario as early as 1974 when the provincial government made a major commitment to provide community living alternatives for individuals with intellectual disabilities. The institutional population in Ontario, then numbering 8,000 across 16 facilities, dropped to 5,200 in the subsequent decade with the closure of five institutions. The community living policy adopted in Ontario was further articulated in the 1987 document entitled “Challenges and Opportunities”. (Ministry of Community and Social Services, 1987) It called for the down-sizing and eventual closure of the province’s remaining institutions within 25 years. It also included a commitment from the province to expand community-based accommodation and services for children and adults with intellectual disabilities over a seven-year period. In 2004, the government of Ontario announced the planned closure of the remaining institutions (then numbering three) by March 31, 2009 noting:


This was not, however, to be accomplished without opposition from concerned parents of residents who feared community supports were not in place to meet the needs of their family members. On September 29, 2005, the Ontario Superior Court put in place a 90-day stay that prevented moving residents from the three remaining facilities without their families’ permission. The case, a class-action suit by a group of parents, was heard further by a panel of three judges in Ontario Divisional Court. (http://www.opseu.org/news/Press2005/dec142005.htm accessed on December 21, 2005) On January 26, 2006, the Honourable Mr. Justice Charles T. Hackman ruled that “the Minister was acting within the authority given to her by section 2 of the Developmental Services Act when she exercised her
discretion to close the three remaining Schedule I facilities, by March 31, 2009.” (Court File No.: 05-DV-1152, 05-DV-1200; DATE: 2006/01/26) Closure activities resumed such that on March 31, 2009 the doors of Southwestern Regional Centre in Chatham-Kent, Huronia Regional Center in Orillia, and Rideau Regional Center in Smiths Falls were closed. On that day, the Minister of Community and Social Services of Ontario, Madeleine Meilleur, proclaimed: “As we close the doors to institutions, we also close the doors to the segregation, seclusion and stereotyping of Ontarians with a developmental disability.”


History, however, tells us that for individuals with intellectual disabilities, living in the community has not necessarily meant being a full participant in one’s community. Research from the late 1990s indicated that in Ontario, many individuals with intellectual disabilities living outside institutions did not have access to integrated services. (Buell & Brown, 2002; Minnes, Buell, Feldman, McColl & McCreary, 2002) A four and a half year longitudinal study across Ontario (1994-1999) showed that while people who had moved from institutions to the community used their communities much more than when they lived in facilities, there were still challenges. Cost, the ability to get around, and especially being accepted were still problematic for some. Furthermore, those who continued to live in the community throughout the study period experienced more difficulty participating in their communities in 1999 than in 1995. (http://www.utoronto.ca/qol/final_summary.pdf accessed August 29, 2005) Hence, over the last few decades, there has been a growing acknowledgement that living in a given community

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3While the Ontario government uses the term ‘developmental disabilities’, intellectual disabilities is used throughout this document to be consistent with the international literature.
consists of more than care delivered in that community; there is an expectation of care by the community and inclusion in society.

Normalization has been criticized for “failing to acknowledge the differential power relationships which are implicated in the process of devaluation and exclusion, and for denying the experience and value of difference.” (Myers, Ager, Kerr & Myles, 1998: 405; Simpson, 1998) A new vision for people with disabilities in Canada is outlined in a Federal/Provincial agreement, of which Ontario is a signatory. (Ministers of Social Services in Canada, 1998) This agreement identifies citizenship as the overarching theme. Advocacy groups in Ontario have hence called for the government to create a new comprehensive framework of policy and funding guided by a principle of ensuring full citizenship to people with intellectual disabilities. (http://www.communitylivingontario.ca/briefs/mcssconsult.html accessed August 29, 2005)

The Ontario government’s response is reflected in new legislation; the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008. This Act speaks to making supports more flexible to give people more choice and independence while ensuring the service system is fair and sustainable. It is based on the premise that “with the right services and supports, [people with intellectual disabilities in Ontario] can participate fully in community life and feel that they truly belong”. (http://www.mcss.gov.on.ca/mcss/english/resources/legislation/ds_leg_08.htm accessed April 17, 2009; http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_08s14_e.htm accessed December 20, 2011)

Reinders (2002) cautions that this ‘new vision’ for intellectual disabilities – adopted in many jurisdictions around the world - “…which claims self-determination, individual choice and the rights of citizenship as it core values”, is necessary though not sufficient for what he terms “the good life” for citizens with intellectual disabilities. He explains that while public policies,
such as the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, create “space for action…opportunities for individuals to take on new institutional roles” (Reinders, 2002: 2), inclusion requires attention to the “politics of culture” – the intersection where the world of politics and culture meet and sometimes collide. He writes of needing to go beyond the protection of citizenship rights for persons with intellectual disabilities to “infus[ing] our institutions with the values of community” (*Ibid*: 4) if inclusion is to become reality for persons with intellectual disabilities.

Advocates in Ontario have challenged public policy in this regard, stating: “[i]n a worldview that recognizes the citizenship rights of people with disabilities, it is a proper role of government to enable the citizen to manage his disability and simultaneously enable the community to include that citizen.” (Community Living Ontario, November 2003) What is meant by citizenship here is not simply the right to vote and to protection under the law (political forms of citizenship) but, rather, what Painter and Philo (1995) refer to as “socio-cultural” forms of citizenship which are “wrapped up in questions about who is accepted as a worthy, valuable and responsible member of an everyday community of living and working.” (Painter & Philo, 1995: 115)

**Previous research on the impact of social inclusion policy.** Studies examining the living conditions of persons with intellectual disabilities as policy shifts emerged were couched in contemporary notions. As such, through the 1970s and 1980s, deinstitutionalization and community integration - leaving a large institutional setting and having a physical presence in the community - informed research which aimed to describe post-institutional adjustment and residential environments. (Landesman & Butterfield, 1987) Earlier research tended to focus on the frequency of use of community resources and participation in community activities using
such measures as the *Community Integration Scale* (Heller & Factor, 1991 as cited in Heller, Miller & Factor, 1998) which assigns a numeric value between 1 and 4 to community integration based on the frequency of outings per week. Little consideration was given to how these factors affected individuals or revealed what the systemic barriers to participation might be. In the 1990s, research slowly began to embrace a more holistic approach that included social interactions and quality of life as measured outcomes of community living. For example, Evans, Todd, Beyer, Felce and Perry (1994) included a measure of friendship networks in their study to track the impact of policy shift towards community-based care in Wales. Rapley and Hopgood (1997) used the *Quality of Life Questionnaire* (Schalock & Keith, 1993 as cited in Rapley & Hopgood, 1997) and the *Neighbourhood Sense of Community Index* (Pretty, Andrewes, & Collett, 1994 as cited in Rapley & Hopgood, 1997) to evaluate a community-based service for persons with intellectual disabilities in Australia.

Today, there is considerable agreement among researchers that integration means

- having meaningful activities, such as work, school or volunteering within one’s community,
- having a social network or membership within the community, and
- being able to access generically available medical or social services within the community rather than attending a center specializing in disabilities.

A critical review of studies of community integration for persons with intellectual disabilities by Myers, Ager, Kerr and Myles (1998) reveals how, until recently, the principle of normalisation has structured not only policy and service provision but also research in the area. Drawing on the principle of normalisation to inform research questions, researchers have tended to focus on the ability of individuals with intellectual disabilities to “enter the world as it is, and
enjoy the rights most people enjoy” with “the onus [being] on them to conform, and on services to enable them to do so.” (Myers et al., 1998: 405) In such studies, “community” has mainly been defined geographically as that space outside institutions; and “integration” has been measured in terms of use of facilities and resources and/or social networks within a geographically defined community. The conclusions are fairly consistent. Whether one examines the experiences of individuals pre and post deinstitutionalization, in various types of support accommodations, or the experiences of individuals who have always lived in the community, one generally finds that “despite being physically present in local communities, people with [intellectual disabilities] often remain, socially, outside looking in”. (Ibid: 393) The contribution of these studies has been largely limited to understanding the individuals with intellectual disabilities’ adaptation to the community versus the community’s responsiveness to them. Furthermore, as argued by Cummins and Lau (2003), research has tended to disregard “the extent to which people [with intellectual disabilities] desire community integration, the satisfaction derived from community integration, or indeed the nature of the community into which people desire to integrate.” (Cummins & Lau, 2003: 152)

Some writers and advocates differentiate integration from inclusion noting for example that

[a]n integrated community is one in which people are a part of the community, but remain in segregated circumstances….Real inclusion means that people with different needs and abilities are not just physically included in the same space and activities, but are also socially accepted so that meaningful human relationships flourish. (Mollenhauer, 2003)

While, it is argued, integration requires that a part conform or be changed to fit into the whole, inclusion “is positioned from a starting point of the whole having many parts but each none the

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4 The term “community” can in fact encompass much more; namely a political entity as well as a geographic, social or psychological sense of place or belonging (see Abraham, 1989; Szivos, 1992).
less is part of the whole. Inclusion...assumes a society which embraces diversity.” (Chenoweth & Stehlik, 2004: 60)

Examinations of the responsiveness of the community to individuals with intellectual disabilities have focused on community attitudes to people with intellectual disabilities. Some studies have reported a lack of awareness of the presence of individuals with intellectual disabilities in the community (McConkey, 1987 as cited in Myers, Ager, Kerr & Myles, 1998), others have noted a sense of discomfort and even hostility felt by the public to the idea of people with intellectual disabilities living in their communities (Leighton, 1988 as cited in Knapp, Cambridge, Thomason, Beecham, Allen & Darton, 1992), still other research has identified a willingness on the part of the community to engage with people with intellectual disabilities as consumers, neighbours or as possible friends (Lutfiyya, 1991). The reasons for such different findings across studies/places and their implications warrant further examination.

Some have examined the role of social capital as a contributor to social inclusion of individuals with intellectual disabilities noting that social inclusion of these individuals further enhances social capital. (Bates & Davis, 2004; Chenoweth & Stehlik, 2004) At the same time, the six components of social capital each have the potential to contribute to the inclusion of individuals with intellectual disabilities. These are:

- participation in the local community,
- reciprocity,
- feelings of trust and safety,
- social connections,
- citizen power, and
community perception.

However, Chenoweth and Stehlik (2004) caution that social capital should not be seen as a panacea for inclusion. They note that “while communities may be high in social capital, they may also exclude people with disabilities as different from other community members.” (Chenoweth & Stehlik, 2004: 67) Bates and Davis (2004) also express reservation with social capital as the answer to social inclusion of individuals with intellectual disabilities. They note a tension between the social inclusion and social capital perspectives on reciprocity in that “[s]ocial inclusion theorists argue that society should nurture relationships between people with [intellectual disabilities] and those without and assert that everyone can feel at home in mainstream society, while social capital theorists do not make this explicit.” (Bates & Davis, 2004: 199) The authors caution that adopting a social capital analysis alone “could lead to a diminished vision that confined bonding relationships to those between peers in a day center and bridging relationships to those that formed between centers, such as at the Special Olympics.” (Ibid: 199) Cummins and Lau (2003) argue that such a view devalues relationships between people who have an intellectual disability. They identify ‘psychological sense of community’ – a concept closely aligned to social capital - as the key construct of interest and insist that, like all of us, persons with intellectual disabilities can be part of many communities but “when people are given free choice they evidence a preference for integration with their own kind, not with the community in general as that is where we experience “feeling that one is part of a readily available, supportive and dependent structure”. (Sarason, 1977: 14 as cited in Cummins & Lau, 2003: 151)

Furthermore, while there is significant agreement on the notion that “it takes a village”, there have been few efforts to explore the relationships between community characteristics and
their effects on the social inclusion of individuals with intellectual disabilities. “The question of how [community] context influences individual outcome is the most important unanswered question in [community] research.” (Ainsworth, 2002: 118) This, in my view, is certainly the case for research related to the inclusion of individuals with intellectual disabilities in their communities. Shinn and Toohey (2003) point out “the pervasive tendency of observers to underestimate the effects of immediate social situations and overestimate the effects of individual dispositions”. (Shinn & Toohey, 2003: 428) They call this phenomenon “context minimization error”: the propensity to attribute causal influences to individual differences in personality, motivation and intellect. The compositional and contextual effects of community settings must be of primary importance when the outcome of interest relates to a sense of belonging to those given entities. Belonging has as much to do about where you are as it does about who you are; and, furthermore, where you are comes to define you. This interplay between structure and agency is explored by Colley and Hodkinson (2001) in their analysis of a British policy to address the social exclusion of disaffected young adults. They argue that Bridging the Gap, a report from the Social Exclusion Unit in Britain, is flawed as it reverses structure and agency thereby “[locating] the causes of non-participation primarily within individuals and their personal deficits”. (Colley & Hodkinson, 2001: 346) The focus on individual deficits, they point out, “denies diversity and individuality, and reduces those it describes to categories and stereotypes”. (Ibid: 346) Colley and Hodkinson (2001) maintain that external causes of exclusion (structure) are much more significant and amenable to intervention. These include the inability of institutions to support all members of the community as well as deep-rooted structural factors in society, such as class, race and gender.
Recognizing the impact of context/community characteristics on social inclusion, it then becomes important to define what is meant by community. How notions of community relate to the concept of social inclusion is outlined in the next section.

**Community and Social Inclusion**

**Community.** The origin of the term community is often associated with the German sociologist Tonnies who in 1887 first published his conception of the terms *gemeinschaft* and *gesellschaft*. Tonnies’ original conception identified *gemeinschaften* or communities as particular types of social networks where individuals are motivated by a shared interest or will such as families and globally dispersed religious groups. In contrast, *gesellschaft* (often translated as *society, civil society* or 'association') referred to other types of social networks that develop where individual self interest dominates. In defining community and society in this way, Tonnies was not concerned with local social systems or finite, bounded physical locations (Johnston, Gregory, Pratt & Watts, 2000). Over time, the term community has, however, also come to be used to refer to a space or defined territory characterized by a social network of interacting individuals; and it is used as such in lay terms including in the social policy arena. In particular, when referring to community living for persons with intellectual disabilities, advocates and policy makers refer to life outside of institutions and engagement in one’s neighbourhood, town or city.

Liepins’ writing about the notion of ‘community’ in contemporary rural studies (2000a, 2000b) identifies further avenues for analysis to understand the relationship between place-based or territorial communities and the meaning of community living for adults with intellectual

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5Ruth Liepins uses ‘community’ in quotation marks to indicate its usage as a constructed (and contestable) concept.
disabilities. The conceptualization offered by Liepins recognizes three ‘mutually constitutive’ dimensions of ‘community’:

- meanings,
- practices, and
- spaces and structures.

In this model, meanings such as belonging and ‘otherness’ legitimate practices; practices being the ways people conduct their economic, social and political life. Practices enable the circulation and challenging of meanings while occurring in spaces and through structures and at the same time shaping those spaces and structures. Spaces and structures, affect how practices can occur and enable the materialization of meanings. Finally, meanings are embodied in spaces and structures. (Liepiens, 2000a: 30)

Social inclusion. As the term suggests, social inclusion, refers to being “in”/part of a social entity. It is typically considered from the perspective of the traditionally ‘excluded’ or the ‘different’ as opposed to the perspective of the dominant social group. Social scientists have approached the question of exclusion of disability, or difference more generally, from a variety of theoretical perspectives. Some have used Marxist theories to explain the exclusion of disabled individuals. The argument is that in a capitalist society, disabled individuals are excluded or marginalized from the production process because they are viewed as unable to be as productive as their able-bodied counterparts. (Oliver, 1996)

Psychoanalytic theories, however, explain exclusion of disabled individuals as an inborn reaction to Other as a means of maintaining the self intact. Wilton’s paper “The constitution of difference: space and psyche in landscapes of exclusion” (1998), while focused on the issue of
neighbourhood opposition to an AIDS hospice, also sheds light on how to examine community acceptance of individuals with intellectual disabilities beyond the siting of a home. Applying psychoanalytic theory (namely Freud’s uncanny and Kristeva’s abject) for thinking about the exclusion of difference, Wilton provides an explanation of reactions to difference/’other’ and its spatiality. He notes how proximity of ‘difference’ provokes anxiety about the integrity of the body and makes vulnerable one’s sense of identity. He suggests that instances of community opposition to ‘outsiders’ can be characterized as boundary maintenance: “moments when a persistent proximate abject or uncanny threatens to overwhelm the boundaries of individual and collective identity”. (Wilton, 1998: 183) Of particular relevance to the current study is research which suggests that a majority of community members learn to accept facilities and their inhabitants suggesting that people’s conceptions of difference can be challenged by proximity, and that the ‘successful’ siting of a group home may not imply integration, but rather a compromise such that the spatial proximity of the home is tolerated by community residents in return for a guarantee that its presence will go largely unnoticed. Finally, Wilton stresses that:

- people are not immediately aware of why they feel the way they do about difference—the origins of these reactions are at least partially unconscious;
- when someone or something identified as different is out-of-place, it brings with it a challenge to an existing psycho-social order;
- proximity can and does promote acceptance because it forces a re-conceptualization of the self/social to incorporate a more nuanced understanding of ‘difference’.

Social constructivism is also used to illustrate why disabled people are oppressed suggesting that “rather than being born with a predisposition to recognize and categorize Other, we learn to categorize through cultural practices”. (Kitchin, 1998: 344; Shurmer-Smith &
Kitchin (1998) draws attention to the socio-spatial construction of disability noting how “space is instrumental in the reproduction, sustenance and resistance of disablist practices.” (Kitchin, 1998: 354)

Regardless of the theoretical approach one takes to understand social exclusion, it is agreed that social inclusion as a goal for adults with intellectual disabilities refers to a subjective sense of place/belonging in a physical locality and it encompasses notions of interactions - relationships and roles, a sense of a “valued presence and participation…within mainstream society”. (Lemay, 2006: 1) Bates and Davis (2004) refer to it as “people … having full and fair access to activities, social roles, and relationships”. (Bates & Davis, 2004: 196)

Some have equated such social inclusion with a notion of “full” citizenship; that is, membership in both a political and socio-cultural sense. (Painter & Philo, 1995) Goodin (1996) has argued for the adoption of a citizenship discourse in lieu of one based on inclusion/exclusion. He stresses that

[t]alking in terms of citizenship fixes attention on what is common and central. It fixes attention on what all citizens share. Talk of ‘inclusion’ and ‘exclusion’, in contrast, fixes attention – and necessarily so – on boundaries and margins, on what differentiates one class of persons from another. (Goodin, 1996: 356)

Cobigo, Ouellette-Kuntz, Lysaght and Martin (2012) call for a shift in the conceptualization of social inclusion. The authors suggest defining social inclusion as a series of

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6Raymond Lemay writes of the application of elements of role theory to the social integration of individuals within intellectual disabilities concluding that “social integration for individuals is best viewed as a sum of a person’s primary and secondary roles within a number of interconnected or disconnected social settings and groups.” (2006: 9)

7As noted earlier, notions of citizenship are very much on the advocacy and policy agenda in relation to services and supports to individuals with intellectual disabilities in Ontario as the system is transformed subsequent to the closure of institutions.
complex interactions between environmental factors and personal characteristics that provide opportunities to

- access public goods and services,
- experience valued and expected social roles of one’s choosing based on his/her age, gender and culture,
- be recognized as a competent individual and trusted to perform social roles in the community, and
- belong to a social network within which one receives and contributes support.

The above review highlights the complexities involved in using terms such as community and social inclusion. These terms are sometimes used interchangeably, and both concepts are contested. While their use cannot be avoided in the current study, in an attempt to avoid taking a specific stance on how the experience of adults with intellectual disabilities should be examined, the concept of the lifeworld is invoked. From the German *Lebenswelt*, lifeworld is “the world as immediately or directly experienced in the subjectivity of everyday life”. (life-world, 2007) The lifeworld includes individual, social, perceptual, and practical experiences. Much can fall under the purview of lifeworld from life satisfaction to belonging and sense of community. As such, the interest is less on predefined notions of social inclusion, belonging or even citizenship but rather on discovering the significance that individuals ascribe to everyday life.

In the next chapter, a systematic review of the literature analyzes the previous research concerned with the lifeworlds of adults with intellectual disabilities in rural communities. The results of this review are combined with the above understanding of community and social inclusion to examine the past and potential role of geography as a discipline (Chapter 3) to inform the study’s underlying methodological approach and procedures (Chapter 4). The rural and small town communities included in the study and the study participants are described in
Chapter 5 followed by the study results presented in chapters 6 to 8. A discussion and conclusions chapter (Chapter 9) then summarizes findings and reviews their relevance to past and current research, theory and policy. Strengths and weaknesses of the present study are identified and a closing comment is provided on what it takes for young adults with intellectual disabilities to be included in rural and small town Ontario at the turn of the 21st century.
Chapter 2: Literature Review

- Rural Lifeworlds of Adults with Intellectual Disabilities

According to a report by the Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat (2007), 50 percent of the world’s population lives outside urban areas. In Canada, the figure is lower with approximately 20 percent of the population living in rural areas.\(^8\) (Statistics Canada, 2008) The migration of younger residents to urban areas for employment or other opportunities is rapidly changing the demographic profile of rural communities. As young adults transition from childhood/school to adulthood/community life after school, they are frequently faced with the decision to leave their home community to pursue post-secondary education opportunities or to find employment.

Little is known about the lives of adults with intellectual disabilities in rural and small town Canada. The few manuscripts (Carrier, 2007; Lord, 1991) and graduate theses (Blessing, 2005; Dupuis, 2004; Owen, 1998) that have been published describing Canadian research on the community experiences of young adults with intellectual disabilities have tended not to consider the unique contribution that a rural environment might have on one’s quality of life or sense of belonging. One exception is the 2-year qualitative study conducted in Manitoba by MacTavish, Mahon and Lutfiyya (2000). In a preliminary paper reporting mainly on their study methodology, the authors note that young adults with intellectual disabilities (22-34 years of age) in rural communities typically had less contact with their families than their counterparts in

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\(^8\) Since 2011, Statistics Canada defines a rural area as that which is outside a population center. A population centre is defined as an area with a population of at least 1,000 and a density of 400 or more people per square kilometre. Source: [http://www.statcan.gc.ca/subjects-sujets/standard-norme/sgc-cgt/urban-urbain-eng.htm](http://www.statcan.gc.ca/subjects-sujets/standard-norme/sgc-cgt/urban-urbain-eng.htm)
urban settings. Unfortunately, this potentially important result is not discussed and the authors note that a full accounting of their results is beyond the scope of the paper.

Understanding the complex nature of social cohesion, social capital, and sense of community in small towns as well as how they relate to the provision of formal and informal supports is complex (Putnam, 2000; Chenoweth & Stehlik, 2004; Tolbert, Irwin, Lyson & Nucci, 2002; Rosenberg, Skinner, Lovell, Everitt, Hanlon & Rathwell, 2005). Particularly troubling is research which suggests that those most dependent on health and social services such as the elderly, and those living with mental illness or disability, face a double disadvantage in rural communities (Gething, 1997). While research of subgroups, such as those with intellectual disabilities, living in rural and small town communities is challenging due in part to the small number of potential research participants, the double disadvantage created warrants attention.

Development in the geographic study of mental health in rural communities is of particular relevance to the experience of adults with intellectual disabilities. Geographers are beginning to examine rural variations in community care, inclusions and exclusions, stigma and identity as it relates to mental health (Philo, 2005) including rural community stress and distress (Jacob, Bourke & Luloff, 1997), and determinants of rural resilience (Wainer & Chesters, 2000). Philo, Parr and Burns (2003) identify three sets of thematic concerns in the rural geography of mental health: rural incidence, rural services and rural lifeworlds.

This chapter examines systematically how researchers have sought to understand issues related to adults with intellectual disabilities in rural communities.
Approach to the Literature

An extensive literature search was conducted. Three major literature databases (Scholars Portal Journal from January 1980 to December 2011, PsychInfo from January 1980 to December 2011, CINAHL from January 1982 to December 2011) were searched using the following combination of subject headings: (intellectual disability or mental retardation or learning disability or developmental disability) and (rural or rurality or small town or geography or place) with results restricted to adults (>=18 years of age). The results were organized under the three themes outlined by Philo, Parr and Burns (2003) and further sub-categorized according to geography (countries). A detailed analysis and discussion of papers categorized under the rural lifeworlds theme is included.

The search identified 165 citations. Upon review of the abstracts, 64 were excluded because they related to children and/or their caregivers only (n=43), were duplicates (n=12), they only described programs or policies (n=5), or they were not focused on intellectual disabilities (n=4). One hundred and one citations were retained for full article review. Following full article review, of the 101 papers, 55 were excluded because they related to children and/or their caregivers only (n=23), they did not have a rural focus (n=15), they were not focused on intellectual disabilities (n=6), their content was included in another article (n=3), or they were descriptions of programs only (n=8). The remaining 46 papers were categorized according to Philo et al.’s three thematic concerns: rural incidence (n=12), rural services (n=21) and rural lifeworlds (n=13). Of the latter 13 papers, six were subsequently excluded from the detailed analysis because they did not include the perspective of adults with ID; leaving only seven papers of direct relevance to the lifeworlds of adults with intellectual disabilities in rural
communities. While reviewing the papers identified through the databases listed above, two more studies concerning lifeworlds were added (see Figure 1).

Figure 1: Flow of Citations through the Publication Identification Process
The papers examining incidence/prevalence and services are briefly summarized in the next section. The papers concerned with lifeworlds retained for analysis are listed in a table and reviewed first to explore how rural and lifeworlds are defined. Findings related to lifeworlds of adults with intellectual disabilities are then presented along with a critique of approaches used. This chapter concludes with recommendations for the current thesis.

Findings

**Rural incidence/prevalence.** Published epidemiologic studies of the occurrence of intellectual disabilities in rural adult populations are rare. The studies identified were predominantly conducted in low or middle income countries, often in the context of broader examinations of neurological or mental health disorders. Three of the twelve studies were conducted in India (Gourie-Devi, Gururaj, Satishchandra & Subbakrishna, 2004; Das & Sanval, 1996; Razdan, Kaul, Motta, Kaul et al., 1994), two in Africa (Patel, Ferrao Simbene, Soares, Weiss & Wheeler, 2007; Fitaw & Boersma, 2006), two in Asia (Lee, 1998; Tao, 1988) and one in the Middle East (Noorbala, Yazdi, Yasamy & Mohammad, 2004). One study, led by the World Health Organization (Fewtrell, Pruss-Ustun, Landrigan & Ayuso-Mateos, 2004), included 14 geographical areas. Finally two studies were conducted in rural Australia (*Estimates of prevalence*, 2004; Wellesley, Hockey, Montgomery & Stanley, 1992) and one in rural Denmark (Dupont, 1989). No Canadian studies were found.

While not an exhaustive review of studies on the rates of intellectual disabilities in rural communities, the above studies highlight a few trends. First, studies reporting on the incidence or prevalence of intellectual disabilities in rural communities tend to be broader studies of neurological or mental health disorders across all ages using screening approaches sometimes followed by clinical assessments. The resulting rates of intellectual disabilities tend to be lower
than expected (from 0.2% in one Indian study to 1.9% in Mozambique). Studies that compare prevalence across urban versus rural areas all report a higher prevalence in rural areas (India: Gourie-Devi, et al., 2004; Mozambique: Patel et al., 2007; China: Tao, 1988; Australia: Wellesley et al., 1991). The paper from Denmark (Dupont, 1989) reports a higher rate in women in rural areas compared to urban areas while the prevalence in men remains the same (and is consistently higher than in women).

**Rural Services.**

While the problems faced by agencies which serve rural areas are comparable with those in urban areas, factors such as low incidence, great distances, and lifestyle diversity make service provision problematic. (See, Ellis, Spellman & Cress, 1990: 54)

In contrast with the studies of rural prevalence, the studies focused on rural services are more numerous and almost exclusively from high income countries. The list reflects a concern for the provision of health services to adults with intellectual disabilities in rural areas of the United States (4 papers: Hilty, 2004; Nord, Wieseler & Hanson, 1998; Clevenger, Wigal, Salvati, Burchill & Crinella, 1994; Rinck & Calkins, 1989) as well as Australia (3 papers: Denham & Shaddick, 2004; Iacono, Humphreys, Davis & Chandler, 2004; Iacono et al, 2003) and the United Kingdom (3 papers: Nicolson & Cooper, 2011; Bell, 2005; Smiley et al., 2002). An additional six papers focused on issues related to employment supports for these individuals almost exclusively in the United States (5 papers: Kinnison, Fuson & Cates, 2005; Gray, McDermott & Butkus, 2000; McDermott et al, 1999; Schalock et al., 1992; Craig & Boyd, 1990) with one paper reporting on rural India (Hanumantha, Venkatesan & Vepuri, 1994). Two studies specifically address services for aging person with intellectual disabilities in rural United States (Cotton & Spirrison, 1998; See et al, 1990). One study reported on legal services in Australia
(Hayes, 1997) and a final paper included in the review examined the impact of funding packages on integration and independence (Campbell, Fortune & Heinlein, 1998).

As persons with intellectual disabilities tend to require lifelong supports from service systems, issues related to service provision in rural areas are relevant to understanding the lifeworlds of those who live in such areas. The following is a brief summary of what the above papers reveal about health services and employment for adults with intellectual disabilities in rural settings.

**Health services.** Studies from the United States document unmet dental needs in both rural and urban settings (Clevenger et al., 1994) and a higher prevalence of antipsychotic drug use among those living in rural areas (Rinck & Calkins, 1989). Of note is that Rinck and Calkins (1989) suggest this finding could be a function of having mainly generalist physicians working in rural areas. Hilty (2004) and Nord et al. (1998) highlight the benefits of telephone and email consultations and support to providers of primary health care and crisis interventions in rural areas of California and Minnesota, respectively.

Through focus groups and interviews, Iacono, Humphreys, Davis and Chandler (2004) revealed the lack of access to knowledgeable primary health care providers in rural and remote areas of Australia. They note that access to care is further reduced due to poor attitudes of providers and communication difficulties. In addition, Australia is concerned about the recruitment and retention of allied health professionals in developmental disability services in rural and remote areas (Denham & Shaddock, 2004).

Studies from Scotland paint a different picture. Smiley, Cooper, Miller, Robertson and Simpson (2002) noted diversity in services provided to persons with intellectual disabilities but found that geographical distance and responsibilities for service provision to remote and rural
communities did not account for these differences. More recently, Nicolson and Cooper (2011) showed that those living in rural areas of Scotland had significantly more contact with primary and secondary health care including dentists and opticians than those in urban areas. The authors acknowledge that the contrast between their study and previous research could be related to how rural and remote are defined. They call for further research to understand how to interpret increase contact; does it represent greater need, better access, better quality, etc.?

Employment. The employment prospects for adults with intellectual disabilities in rural America appear rather bleak. McDermott, Martin and Butkus (1999) showed that variability in employment among adults with intellectual disabilities in South Carolina across counties is partly explained by the percentage of the county population living in rural settings. Gray and colleagues (2000) demonstrated that the effect of coaches on employment likelihood in the same State was 10 times greater for individuals located in highly urbanized counties; thereby concluding that expenditures on job coaches may not be effective in rural settings and that emphasis should be placed on offering non-competitive employment to adults with intellectual disabilities in rural communities. Finally, Schalock, Holl, Elliott and Ross (1992) followed graduates from rural special education programs and found those with mild intellectual disabilities were more likely to be unemployed and, if employed, to work part-time and receive a significantly lower hourly wage than their counterparts with specific learning disabilities.

The finding by Craig and Boyd (1990) that, in the State of Washington, the proportion of urban and rural employers hiring persons with handicapping conditions, including intellectual disabilities, did not differ significantly suggests systemic factors are involved. Kinnison and colleagues (2005) attribute the situation to the lack of occupational diversity, limited industry, and limited or no public transportation in rural communities.
The paper by Hanumantha and colleagues (1994) describes a pilot project in India which demonstrates the potential for coordinating and incorporating State/Central Government schemes for rural development along with employment opportunities for rural adults with intellectual disabilities.

**Rural lifeworlds.** While 13 studies retained were categorized under the heading of rural lifeworlds, only nine focused on the experiences of adults with intellectual disabilities (see Tables 1 and 2). The nine studies listed in Table 1 form the basis of the following analysis of lifeworlds of adults with intellectual disabilities in rural communities. This category (rural lifeworlds) is populated by studies from the United States (n=2), Australia (n=4), Canada (n=2; both in Manitoba) and Sweden (n=1).
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Year</th>
<th>Title</th>
<th>Geography</th>
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<tbody>
<tr>
<td>Eley et al.</td>
<td>2009</td>
<td>Accommodation needs for carers of and adults with intellectual disability in regional Australia: their hopes and perceptions of the future</td>
<td>Australia</td>
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<tr>
<td>Stromberg et al.</td>
<td>2005</td>
<td>Social needs of people with severe functional impairments living in a rural district in Sweden: A population-based study</td>
<td>Sweden</td>
</tr>
<tr>
<td>Kellow &amp; Parker</td>
<td>2002</td>
<td>Self-perceptions of adequacy of support among persons with mental retardation living in suburban versus rural communities</td>
<td>USA</td>
</tr>
<tr>
<td>MacTavish et al.</td>
<td>2000</td>
<td>&quot;I Can Speak for Myself&quot;: Involving Individuals with Intellectual Disabilities as Research Participants</td>
<td>Canada-Manitoba</td>
</tr>
<tr>
<td>Rapley &amp; Hopgood</td>
<td>1997</td>
<td>Quality of life in a community-based service in rural Australia</td>
<td>Australia</td>
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<tr>
<td>Ralph &amp; Hopgood</td>
<td>1995</td>
<td>Social interactions of persons with developmental disabilities living independently in the</td>
<td>Australia</td>
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</tbody>
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Based on the doctoral dissertation of Kellow, 1997.
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Year</th>
<th>Title</th>
<th>Geography</th>
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<tbody>
<tr>
<td>Usher</td>
<td></td>
<td>community</td>
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<tr>
<td>Leibowitz et al.</td>
<td>1994</td>
<td>Client perceptions of quality of life in accredited and nonaccredited community residential facilities</td>
<td>USA</td>
</tr>
<tr>
<td>Ashman et al.</td>
<td>1990</td>
<td>The life circumstances of aged people with intellectual disabilities</td>
<td>Australia</td>
</tr>
<tr>
<td>Chornoboy &amp; Harvey</td>
<td>1988</td>
<td>Relationship between the housing facility type of aging persons who are developmentally disabled and their activities</td>
<td>Canada-Manitoba</td>
</tr>
</tbody>
</table>
Table 2: Listing of Studies of Rural Lifeworlds of Adults with Intellectual Disabilities – Excluded

<table>
<thead>
<tr>
<th>Author (s)</th>
<th>Year</th>
<th>Title</th>
<th>Geography</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lloyd</td>
<td>2009</td>
<td>How the all fruits salad creates sweeter futures in rural and remote mental health</td>
<td>Australia</td>
</tr>
<tr>
<td>Minnes &amp; Woodford</td>
<td>2004</td>
<td>Well-being in aging parents caring for an adult with a developmental disability</td>
<td>Canada</td>
</tr>
<tr>
<td>Finnegan et al.</td>
<td>2004</td>
<td>The impact of formal services on family carers of individuals with intellectual disability</td>
<td>Ireland</td>
</tr>
<tr>
<td>Gammon</td>
<td>2000</td>
<td>Examining the needs of culturally diverse rural caregivers who have adults with severe developmental disabilities living with them</td>
<td>USA</td>
</tr>
<tr>
<td>Sinson &amp; Stainton</td>
<td>1990</td>
<td>An investigation into attitudes (and attitude change) towards mental handicap</td>
<td>England</td>
</tr>
<tr>
<td>Aveno</td>
<td>1987</td>
<td>A survey of leisure activities engaged in by adults who are severely retarded living in different residence and community types</td>
<td>USA</td>
</tr>
</tbody>
</table>
Discussion

Defining rural. One of the first observations when combining information from such diverse studies is the lack of consensus on what constitutes rural. In most cases (n=6), rural is not defined; authors refer to rural districts, country towns or rural areas. This is not unusual; in a similar review of published papers on rural mental health, it was found that 43 percent did not define the rural they discussed (Bosak & Perlman, 1982). When rural is defined, the review further shows that authors prefer to use local or homemade definitions, as opposed to external quantitative definitions, such as the definitions provided by government statistical agencies. For example, Statistics Canada (2008) defines rural areas as “sparsely populated lands lying outside urban areas”; that is, those areas with a population density of up to 400 per square kilometres. A similar definition by exclusion is provided by the US Census Bureau. In the current review, the two included American studies defined rural quite differently. One indicated that rural areas had 1,000 residents living approximately 1.5 hours from a metropolitan area (Kellow & Parker, 2002) while the other considered communities with less than 15,000 population to be rural (Leibowitz, McClain, Evans & Ruma, 1994). The one Australian study providing a definition, characterizes as a country town “a coastal town of approximately 10,000 persons” which the authors contrast to metropolitan locations (Ralph & Usher, 1995).

Defining the scope of lifeworld. The nine studies included examined/reported on belonging (Stromberg, Sandlund & Westman, 2005; Rapley & Hopgood, 1997; MacTavish, Mahon & Lutfiyya, 2000), social interactions (Ralph & Usher, 1995), self-esteem (Stromberg et al., 2005), energy (Stromberg et al., 2005), perceptions of adequacy of supports (Kellow & Parker, 2002; Eley, Boyes, Young & Hegney, 2009), sense of community (Rapley & Hopgood, 1997), quality of life (Leibowitz et al., 1994), happiness (Eley et al., 2009), choice (Eley et al.,
leisure activity and preferences (Chornoboy & Harvey, 1988), as well as contact with and/or role within one’s family (Ashman, Hulme & Suttie, 1990; MacTavish et al., 2000; Eley et al., 2009), access to community and normality of life (Ashman et al., 1990) as the scope of one’s lifeworld. While by definition lifeworld can consist of innumerable elements, when applied to adults with intellectual disabilities a common element considered is the connections they have with others.

Understanding the lifeworlds of adults with intellectual disabilities in rural areas.

To understand lifeworlds, comparisons are sometimes made. One study compared adults with intellectual disabilities to other groups, namely those with mental health or physical problems living in the same rural area. (Stromberg et al., 2005) Others compared rural dwellers with intellectual disabilities to those living in suburban areas (Kellow & Parker, 1997; Rapley & Hopgood, 1997; Ralph & Usher, 1995) or cities (MacTavish et al., 2000; Leibowitz et al., 1994; Ashman et al., 1990). Still others contrast the experiences of individuals with intellectual disabilities in rural areas living in different accommodation types. (Rapley & Hopgood, 1997; Eley et al., 2009)

The earliest of the included studies was published in the late 1980s. While Chornoboy and Harvey (1988) examined the activity preferences of older adults with intellectual disabilities in rural Manitoba using a novel interview approach, their study did not speak specifically to rurality. No comparison was made to non-rural dwellers and the authors do not discuss their findings in relation to the size, location, or nature of the communities where the participants lived. More recently, other researchers from Manitoba (MacTavish et al., 2000) undertook a 2-year study grounded in a qualitative framework to enhance understanding of social integration by including the perspectives of individuals with intellectual disabilities. They used multiple
strategies (interview guide approach, focus groups, verification meetings) to collect information and to confirm, with the participants, how well the emerging findings reflected their views. The 32 participants aged 17 to 82 years were “drawn equally from a large urban center in Western Canada and a collection of small towns and rural settings”. (p. 218) While the focus of the project was not urban/rural distinctions, the authors note two relevant observations:

- “In urban settings, families tended to be more actively involved in the lives of their children well into their mid-30s, whereas rural participants typically had less contact with their families by the time they were in their early 20s.” (MacTavish et al., 2000: 224);
- Service providers believed that rural communities were more conducive to social integration than urban centers; a sentiment that was not shared by adults with intellectual disabilities.

These Canadian observations beg further examination.

In Australia, the question of rurality appears to have been more prominent in inquiries into the experiences of adults with intellectual disabilities. In the 1980s, Ashman and colleagues (1990) set out to describe the experiences of 50 adults with mild or moderate intellectual disability over the age of 50 in rural (n=19) and metropolitan (n=31) areas of Queensland, Australia. Interviews were conducted with the adults and/or a caregiver. Contrary to the Manitoba findings, the authors found that rural parents “seem[ed] keen to keep their aging offspring within the family infrastructure rather than seeking accommodation in more populated areas”. (Ashman et al., 1990: 338) For rural participants, contact between members of the families was far more frequent than for the city dwellers and the regularity of access to community services was greater. The authors concluded that “[p]roportionately, those people in
the rural sample appeared to live more normalized lives than those in the city, based upon access to, and participation in, activities away from their residences”. (Ashman et al., 1990: 340) Ralph and Usher (1995) similarly found that adults (18 to 59 years old) within intellectual disabilities in a country town in Western Australia (n=19) interacted with more people without disabilities than those living in an outer suburban community (n=20).

Another Australian study (Rapley & Hopgood, 1997), applied a number of tools to capture aspects of the lifeworld of 34 adults (21-54 years old) with intellectual disabilities (levels of ID not provided) in community residences in either suburban (n=2 residences) or rural (n=3 residences) areas. Their *a priori* hypothesis that rural residences would provide a higher sense of community was not supported. However, the residence-by-residence comparisons showed that the smallest residence (rural with only six adults; all others had 12 adults) was superior on sense of community. The authors commented that the rural versus urban may have been insufficiently fine-grained and as such had failed to take account of the difference between rural communities and the size of community residences. Another finding was that the abilities of the adults accounted for a very small amount of the variance in quality of life scores leading the authors to suggest that “it appears that factors other than merely service user attributes are influential”. (Rapley & Hopgood, 1997: 132)

The most recent study was also from Australia. Eley and colleagues conducted in-depth interviews with ten adults with intellectual disabilities (meant to represent a group of 156 individuals 18 to 79 year olds) living in regional/rural Australia about their experiences and perceptions regarding their accommodation needs and future lifestyle issues. They also interviewed their caregivers. The importance of family to both adults still living with their family and those living away from their family was apparent. In particular, adults with intellectual
disabilities valued their contribution to the family but also expressed concern about their family caregiver’s quality of life. They identified transportation as a barrier to involvement in their community.

The largest study concerned with the lifeworld of adults with intellectual disabilities was undertaken in Nebraska. The goal was to examine the quality of life of adults (n=146; 16-68 years old) with mild to profound intellectual disabilities. (Leibowitz et al., 1994) The researchers used self reports for those who could be interviewed and the average score of two proxies for those who could not be interviewed due to their disability. When all measures of quality of life were combined (self and proxy), no differences were seen between rural (n=39) and urban (n=107) adults. When only self reports were included, individuals living in rural locations rated themselves as having a higher quality of life than persons living in urban areas. The authors do not discuss this very interesting finding. A subsequent case study of eight adults with mild intellectual disabilities (20-47 years old) living in supported apartment settings in either a rural community (n=4) or a suburban community (n=4) in south east Texas (Kellow & Parker, 2002) was not as favourable to rural settings. It revealed that rural dwellers report lower perceptions of adequacy of support while making the same use of formal supports as those living in suburban areas. The case study also showed that fewer of the rural participants were employed due to lack of opportunity and lack of efficient transportation.

Finally, a study from Sweden, sought not to compare lifeworlds based on rural/urban categorization but rather across disability groups. In a rural district, Stromberg et al. (2005) found that when comparing adults (18-65 years of age) with intellectual disabilities (n=19; level of disability not provided) to those with physical disabilities (n=23) or mental health problems (n=55; 3 of whom also had an intellectual disability), sense of belonging, self-esteem and energy
were highest among those with intellectual disability. The authors caution that their findings might be an artifact of measurement as they cannot eliminate the possibility of acquiescence bias, or difference in understanding or in insight across the three groups.

Many approaches can be taken to learn about the lifeworld of a group of citizens. Given the subjectivity of lifeworld itself, one would expect that it would be best examined using qualitative methodology. However, with the exception of Kellow and Parker (1997)’s case study and MacTavish and colleagues’ participatory approach (2000), the inquiries into the lifeworlds of adults with intellectual disabilities have relied on quantitative methods. A variety of instruments including pictorial questionnaires (Chornoboy & Harvey, 1988), diaries (Ralph & Usher, 1995), and structured interviews (Rapley & Hopgood, 1997; Stromberg et al., 2005; Leibowitz et al., 1994; Ashman et al., 1990) have been used to count and average experiences and perceptions reported by adults with intellectual disabilities and/or their caregivers. These positivist and structuralist approaches have failed to examine critically the forces shaping experiences and perceptions.

**Advancing our understanding.** The literature specifically addressing the lifeworlds of adults with intellectual disabilities in rural areas is sparse. The inconsistency of findings across study designs, measures and locations suggests that much more research is needed. It remains unclear whether living in a rural area contributes positively or negatively to the lifeworlds of adults with intellectual disabilities.

The notable absence of studies from low and middle income countries calls to mind the challenge to geographers of disability studies made by Park, Radford and Vickers (1998), a decade ago, to embrace the emancipatory paradigm and turn our attention to issues of social justice and ethics. While studies categorized under the theme of rural services are limited in their
ability to address such issues, they do contribute to an understanding of formal supports available and common barriers to access. The findings from such studies are, however, quite consistent and not too surprising; employment opportunities are limited and lack of transportation hinders participation.

There are several challenges to undertaking research to shed light on the rural lifeworlds of young adults with intellectual disabilities. As noted by Conroy and Bradley, “among the many ways that the well-being of people with [intellectual disabilities] may be assessed, one that stands out in importance and in difficulty is to ask the people themselves. (Conroy & Bradley, 1984 as cited in Leibowitz et al., 1994: 340) This is apparent in a number of the included studies. Kellow and Parker (2002) stand out in addressing this issue partly by using multiple sources of information and triangulating their data.

Comparisons with other groups may not be appropriate given the differences in ability to understand and express oneself in relation to complex concepts such as sense of community or quality of life. Comparisons among adults with intellectual disabilities living in different settings (urban/rural) may be more enlightening. However, as pointed out by Rapley and Hopgood (1997), it is important to consider the nature of the specific communities. This was done by Kellow and Parker (2002) whose case study considered the community as the unit of analysis and viewed the individuals with intellectual disability as embedded within the community.

The issue of sample size when conducting quantitative analyses of information about the lifeworlds of adults with intellectual disabilities in rural communities cannot be underestimated. The number of adults with intellectual disabilities in rural areas included in the studies ranged from four in Kellow and Parker’s case study in Texas (Kellow & Parker, 2002) to 36 in Leibowitz and colleagues’ random sample survey in Nebraska (Leibowitz et al., 1994). All the
studies testing differences across groups were significantly underpowered for the analyses they conducted. (Stromberg et al., 2005; Rapley & Hopgood, 1997; Ralph and Usher, 1995; Leibowitz et al., 1994) This is particularly problematic for Rapley and Hopgood (1997), and Leibowitz and colleagues (1994) who rejected their null hypotheses as it increases the risk of a Type II error (failing to observe a difference when in truth there is one). Since it appears important to control for the community of interest itself in any analysis, quantitative studies of the lifeworlds of adults with intellectual disabilities are unlikely to yield sound results as any one community is likely to have a small number of potential study participants and rates of participation in research for this group tend to be low (10% to 30%).

A way forward is to apply Kellow and Parker’s case study approach and combine multiple voices that can reflect on the lifeworlds of adults with intellectual disabilities in their communities. These voices should include the individuals themselves, their families and/or caregivers, as well as other members of the community. A focus should be placed on understanding the influence of the community itself in shaping the lifeworlds of all its members.
Chapter 3: Geography, Rurality and the Lifeworlds of Young Adults with Intellectual Disabilities

Human geography can make a distinctive contribution to the study of community effects such as rurality on the lifeworlds of young adults with intellectual disabilities as it offers “a theorized sensitivity to the entangled relations of mental health, society, space and environment”. (Philo, 2005: 585) A geographical framework can enhance our understanding and definition of key concepts related to space and place (rurality and lifeworlds) to be used in such research.

As noted in the literature review, rurality is too often a taken for granted concept. Whether defined according to physical features (distance to larger centers), demographic criteria (population density), in sociological terms such as by the nature of what the residents do (farming, agriculture), or a combination of these, there tends to be an assumption that describing a community as rural implies it is more similar to other so defined communities than it is to suburban or urban communities in all respects. Human geography’s unique perspective on place calls us to challenge this assumption. Agnew’s (1987 as cited in Johnson et al., 2000) three major elements of place: locale, location and sense of place provide a framework for conceptualizing the rural. As such, rural places are best described as at once settings in which social relations are constituted (locale), geographical areas encompassing the settings for social interactions (location), and local structures of feeling (sense of place). Furthermore, geographers’ definitions of place emphasize heterogeneity and fluidity of boundaries. A geographical perspective on rural places draws attention to structure-agency, nature-society, and self-other interconnections.

\[10\] Here Philo includes intellectual disabilities as a sub-field of mental health.
The contribution of human geography’s conception of place is not only pertinent to understanding what is meant by rural but it is also critical to theorizing about lifeworlds. While geographers have, since the 1980s, written about intellectual disabilities reiterating the importance of examining the experience of place by individuals with intellectual disabilities (Wolpert, 1980; Laws and Radford, 1998; Walker, 1999; Hall, 2004), their work has not addressed rurality specifically. The next section provides a chronology of geographers’ interest in issues affecting this population.

Julian Wolpert’s 1980 essay entitled “The dignity of risk” is considered a key publication to have brought intellectual disabilities to the attention of academic geography. (Philo & Metzel, 2005) In discussing responses to social and natural hazards within a common framework (using the concepts of competency and dangerousness), Wolpert challenges the concerns for self-harm and threat to others posed by persons with intellectual disabilities (then called mentally handicapped) which resulted/s in incarceration/ institutionalization. The essay does not reveal why Wolpert chose to include the treatment of persons with intellectual disabilities as a case along with natural disasters, nuclear accidents and bankruptcy, to support his argument that “[G]eographers as well as other social scientists should be able to analyze each new programme in terms of its distribution of risky impacts and the resulting equity implications…” (Wolpert, 1980: 397)

The inclusion of persons with intellectual disabilities was likely influenced by Wolpert’s earlier investigation of neighborhood property impacts of group homes for persons with intellectual disabilities which he conducted for the New York State Office of Mental Retardation and Developmental Disabilities. (Wolpert, 1978) The concluding statement in Wolpert’s seminal essay suggests a deep concern for the lived experiences of this vulnerable group. He writes
“…the pursuit of recreation, hobbies, leisure, good times, friends and family has not yet become very hazardous”. (Wolpert, 1980: 400)

Since the 1980s, historical and social geographers such as Chris Philo and Deborah Metzel have written about the experiences of individuals in asylums and about the process of residential relocation through the 70s, 80s and 90s in England and the United States, respectively, at times commenting on implications for intellectual disabilities. Metzel and Walker (2001) caution against generalizing the work related to the geography of mental illness to that of intellectual disabilities. Philo (2004) similarly stresses that there are many important differences in the histories and historical geographies of mental illness and intellectual disabilities. He directs readers to the work of Radford and Park.

John Radford and Deborah Park are two key names in the studies of intellectual disabilities, mental illness and asylums in Canadian human geography. They have written about the history of intellectual disabilities in Ontario (Radford & Park, 1999), the eugenic legacy (Radford & Park, 1995) and asylums (Park & Radford, 1997). In their review of disability studies in human geography, Park, Radford and Vickers (1998) place intellectual disabilities under the heading of geography and mental health highlighting the historical focus on the historical geography of intellectual disabilities closely linked to the history of mental health asylums in the UK and North America.

Only two publications by geographers address the experience of persons with intellectual disabilities in Canada. Micheal Dear and Jennifer Wolch (Dear & Wolch, 1987) included an analysis of the experiences of individuals with mental retardation in Hamilton, Ontario in the 1980s in their book, Landscapes of Despair, where they present case studies of deinstitutionalization of various populations in several cities in the United States and Canada.
As they could only locate 522 persons with intellectual disabilities (then called persons with mental retardation) receiving services in Hamilton from the expected 9,196, it is not surprising that Dear and Wolch devote only two pages of their chapter entitled "Anatomy of the service-dependent ghetto" to this group. They map geographic clustering of service-dependent populations including those with intellectual disabilities and reflect on the history of asylums and deinstitutionalization. Laws and Radford (1998) have published the only account of the experience of community living for adults with intellectual disabilities in Ontario by geographers. Their interviews with 57 adults living in Toronto concluded that while the disabled label most clearly defined their social networks, their needs and desires were not so different from the 'so-called normal population'.

Laws and Radford have criticized the geographical community for its neglect of intellectual disabilities “...especially in comparison to studies of other marginalized groups such as the mentally ill.” (Laws & Radford, 1998: 80) Hall and Kearns concur that until recently, research into the geographical experiences of individuals with intellectual disabilities has been “at best, a footnote to debates on post-asylum geographies”. (Hall & Kearns, 2001: 238) In a review of the work of geographers in the field of intellectual disabilities prior to 2000 aptly titled “Making space for the ‘intellectual’ in geographies of disability”, Ed Hall and Robin Kearns (2001) point out that while the geography of disability is an established sub-field of human geography rich in discourse on issues ranging from physical accessibility of public spaces, the role of body identity, and the cultural construction of disability; it has not considered all forms of disability equally. The focus of geographers has been to examine the experiences of those with physical and sensory impairments often in the context of exploring productivity roles and physical access. Others have written about the experiences of those suffering from mental illness
largely in relation to institutionalization, deinstitutionalization and siting of services. Park, Radford and Vickers (1998) provide a comprehensive overview of this earlier work noting a shift in predominant paradigms adopted by geographers from positivist to interpretative and emancipatory. They challenge geographers of disability studies to embrace the latter paradigm by turning their attention to issues of social justice and ethics.\[11\]

The dedication of a section of an issue of Health & Place (2005, volume 11) to the theme of geographies of intellectual disabilities reflects a renewed interest by geographers to the ongoing socio-spatial exclusion of this population. In addition to the editorial and an essay, the issue includes three papers depicting the geographies of intellectual disabilities in three different countries. Deborah Metzel (2005) writes of the negative consequences of service dependency and social poverty re/created by a well-intentioned community-based voluntary organization supporting adults with intellectual disabilities in Baltimore, USA in the early 1990s. Hall (2005), referring to qualitative research in Scotland between 2002 and 2003, concurs that social inclusion policy in that country has in fact resulted in the social exclusion of persons with intellectual disabilities. Finally, Inge Komardjaja (2005) comments on the stigmatization of intellectual disabilities in Indonesia where institutionalization and segregation prevail.

These recent studies have been influenced by Laws and Radford who in 1998 insisted on the need to examine the experience of place by individuals with intellectual disabilities. Hall and Kearns (2001) summarized Laws and Radford's contribution into these pointers for researchers:

- listen to the ‘voices’ of those rendered invisible;

\[11\] Such issues would relate to civil rights, citizenship, and radical politics as informed by the disability rights movement.
‘hold’ the dual notion of the lives and experiences of disabled people as similar AND
different to non-disabled people’s lives; and

understand and represent the diversity of experiences of disabled people.

The focus on capturing persons with intellectual disabilities’ experiences of place through
their own voices has led to the emergence of a body of knowledge that indirectly provides an
appreciation for the contribution of place characteristics to one’s sense of community. The work
of Pam Walker and Ed Hall is of particular relevance.

Through in-depth interviews, Walker (1999) explored the experiences of seven adults
with intellectual disabilities (24 to 60 years of age) of various community places. She identified
a sense of safety, identification, familiarity, being known, feeling accepted and a sense of
accommodation as contributors to positive experiences or sense of place. She further noted that
“these experiences tended to occur in places that the informants went of their own choosing,
including private or small-scale public places that they went on a regular basis and places
characterized by a social interaction orientation.” (page 6 of 9 in html text). Finding that the
individuals she interviewed had few opportunities to make such choices and lacked supports to
go to desired community places, she offers a set of strategies for service providers and caregivers
(see Table 3).
Table 3: Strategies for Increasing People's Sense of Place and Community Connections (from Walker, 1999)

<table>
<thead>
<tr>
<th>Promoting Safety, Familiarity and Identification</th>
<th>Promoting A Sense of Being Known and Accepted</th>
<th>Promoting Accommodation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assist people to receive services in the homes, neighborhoods and communities of their choice.</td>
<td>Assist people to be part of shared social contexts and networks encompassing both public and private spheres.</td>
<td>Support and/or develop “natural” sources of support.</td>
</tr>
<tr>
<td>Interweave both natural (informal) and formal sources of support.</td>
<td>Give people increased choice and control over the support they receive.</td>
<td></td>
</tr>
</tbody>
</table>

Hall (2004) explored the social geographies of individuals with intellectual disabilities in the context of social inclusion policy in Scotland using the method of “narrative building”. He concluded that “the policy of social inclusion establishes criteria that many [persons with
intellectual disabilities] cannot or do not want to fulfill, and at the same time, marginalizes the alternative spaces and roles that many generate.” (Hall, 2004: 304) He calls geographers to respond to this through “a sustained critique of the employment-focused social inclusion strategy for [persons with intellectual disabilities]...and through a strong advocacy of the broad notion of social justice and access”. (Ibid: 304)

Pam Walker’s 1999 study exemplifies the distinct perspective geographers bring to the study of lifeworlds. Unlike the reviewed papers on the lifeworlds of adults with intellectual disabilities in rural areas, Walker’s paper goes beyond simple descriptions of activities and perceptions. She offers a critical analysis using a place context; that is, her approach recognizes the interplay between settings for social interactions, areas where these settings are located and the feelings these engender among residents. This type of analysis is the kind of attention required to understand the lifeworlds of adults with intellectual disabilities in rural communities. Such research should not pre-define what is meant by rural but capture it as part of describing the lifeworlds. Furthermore, researchers seeking to understand the experience of place by individuals with intellectual disabilities should be mindful of Laws and Radford (1998) advice noted previously.

Ruth Liepins’ work in rural geography, while not specific to intellectual disabilities, provides a comprehensive and dynamic depiction of community which captures both the context and the outcome under study in the current project. I have adapted her framework (see Figure 2) to guide the interpretation of results (Chapter 9: Discussion and Conclusions).

In the adapted framework, the context is everything; meanings, practices, spaces, and structures as well as their interaction in a given place. The outcome is the particular impact of these constructs on adults with intellectual disabilities in those places. To be consistent with the
social policy discourse of community living for persons with intellectual disabilities, which refers to life outside of institutions and engagement in one’s neighbourhood, town or city, this study uses the term community to mean distinct geographically-bounded/census-defined spaces or what Liepins terms “temporally and locationally specific terrains of power and discourse.” While community will be used to refer to the context provided by a place/town, experience of social networks (Tonniès’ *gemeinschaft* and *gesellschaft*) within these places/towns will be referred to as sense of belonging (what Liepins terms community).
Figure 2: Framework adapted from Liepins (2000b)

1. MEANINGS (Attitudes towards ID) legitimate practices
2. PRACTICES (including ways in which supports to persons with ID are provided) enable the circulation of MEANINGS (Attitudes)
3. PRACTICES (including Supports) occur in spaces and through structures, and shape those spaces and structures
4. SPACES and STRUCTURES affect how PRACTICES occur
5. SPACES and STRUCTURES enable the materialization of MEANINGS
6. MEANINGS are embodied in SPACES and STRUCTURES
Chapter 4: Methods

Underlying Methodological Approach

A phenomenological approach was chosen as the underlying methodology to learn about the meaning of community for young adults with intellectual disabilities in rural/small town Ontario. Using hermeneutical phenomenology, I set out to develop a composite description of the essence of their experience – what they experience and how. Having used both quantitative and qualitative approaches to gather information and develop texts, hermeneutics provides the principal approach for combining the evolving understanding of the phenomenon under study. As such the study used an interpretivist framework. As the experience was explored in the context of specific small towns/rural communities, a multiple case studies design guided the selection of participants, data collection and analysis, as well as the presentation of results.

I was drawn to hermeneutics as described by Gadamer as it allowed me to fuse what is real and important for me with my participants’ construction of reality. Ronald Bonteko (1996: 102) writes that according to Gadamer,

[t]he reader, if she is being fair to the text, will always strive to make it seem reasonable. But of course, what seems ‘reasonable’ and what does not will depend in turn on the reader’s own prior understanding of the subject matter. The text, in other words, never simply has its say; it is always taken in one way or another. And how it is taken reflects at least in part, what the reader would be inclined to say in her own right.
Some elements of Habermas' critique of Gadamer's hermeneutics (Misgeld, 1991) were also helpful; in particular, the notion of suspicion\textsuperscript{12}. I felt the latter was relevant because of the threat of social desirability in responding to interviews given the climate of political correctness, as well as the tendency of individuals with intellectual disabilities to acquiesce in an effort to please the interviewer, to answer succinctly and to respond concretely. (Atkinson, 1988) This meant that I had to be prepared to “read between the lines”. (Paterson & Higgs, 2005) Hermeneutics, with its basis in biblical text studies, provides for an understanding of text (language/interview transcripts) that may in fact be deeper or go further than the author’s own understanding. It recognizes that the author’s (in this case the interviewee’s) meanings and intentions may remain implicit and even go unrecognized by the authors (interviewees) themselves.

The premise for my study is that one cannot examine a phenomenon such as sense of community without relating the individual’s experience to the community itself and the characteristics of the community to the individual’s experience. Gadamer’s hermeneutics rule states that “[w]e are to extend the unity of understanding in ever-widening circles by moving from whole to part and from part to whole.” (Crotty, 1998: 104) This was accomplished by using a hermeneutics spiral to guide the analysis (Figure 3).

Hermeneutical phenomenology calls for the researcher to “interpret the ‘texts’ of life” (interview transcripts) and “mediate between different meanings” (those of different individuals

\textsuperscript{12} “Its implications for hermeneutics is that one has to be upfront and critically reflective about the complicity of language in distorting communication and entrenching prejudice, authority and the domineering tradition.” From Towards a Creative Hermeneutic of Suspicion: Recovering Ricoeur's Intervention in the Gadamer-Habermas Debate by Purushottama Bilimoria
http://www.bu.edu/wcp/Papers/Cont/ContBili.htm accessed on June 24, 2012)
with intellectual disabilities in different localities and of different other groups – caregivers and other community members) using an interpretive cycle. (Van Manen, 1990)

Phase 1 of the hermeneutics cycle was accomplished in Chapters 1 to 4. Phases 2 to 4 of the cycle are executed in chapters 6 to 8. Phase 2 adopts a descriptive quantitative approach to the data on sense of community (Chapter 6). For phases 3 (latter part of Chapter 6 plus Chapter 7) and 4 (Chapters 8) of the hermeneutics cycle, in addition to applying a descriptive approach to quantitative data (e.g., social interaction and belonging measures, and census information) procedures outlined by Moustakas (1994 as cited in Creswell, 2007) are applied to the qualitative interview data. As suggested by Moustakas, after reading and re-reading interview transcripts, significant statements were highlighted and from these statements clusters of meaning were developed. Then, textual descriptions (what is experienced) and structural descriptions (how it is experienced: conditions, situations, contexts) were written for each community. In the final step, these descriptions were combined to reflect the essence of social inclusion/belonging for young adults in rural communities.
Recognize need for greater understanding of social inclusion of young adults with ID in rural communities

Clarify research questions and data sources

Answer research sub-question 1

Answer research sub-questions 2

Applying geographic literature to understand issues influencing social inclusion

Phase I Analysis
- Policy documents
- Literature review
- Methodological Approach

Phase 2 Analysis
- Measure of Sense of Community

Phase 3 Analysis
- Interview data about experiences of young adults with ID

Phase 4 Analysis
- Detailed descriptions of community contexts

Fusion of Horizons 1:
Identify key constructs

Fusion of Horizons 2:
Identify variations across groups

Fusion of Horizons 3:
Interpret sense of community across distinct towns

Fusion of Horizons 4:
Re-interpret sense of community across distinct towns

Figure 3: Adaptation of the Hermeneutics Cycle as described by VonZweck et al. (2008)
Research Procedures

**Site and participant selection.** Purposeful sampling to document diverse variations and identify important common patterns was used. Three towns were selected for their distinctive character. One is more remote (no urban center within 90 minutes), one was the site of an institution for persons with intellectual disabilities until the 1990s, and one has a unique history of community development. Each is located in a different administrative region (county). One is a commercial and service hub for neighbouring smaller towns; one is changing rapidly with an increase in tourism and related industries and in-migration of older persons from cities at retirement; while the other is experiencing a loss of industry, high unemployment and increased commuting for work in a nearby urban center.

Within each town, stratified purposeful sampling was used in order to illustrate perspectives of various subgroups and facilitate comparisons (individuals with intellectual disabilities, their caregivers, other community members). Developmental service agencies\(^\text{13}\) in the three towns were asked to invite young adults with intellectual disabilities and/or their families to participate in the study. To be eligible, the adult with an intellectual disability had to live in the town of interest, be less than 30 years of age, and not be attending school. The same agencies were asked to identify prominent community members who could offer distinct perspectives on the town to serve as key informants. Finally, snowball or chain sampling was used to recruit participants within the strata.

\(^{13}\) These are transfer payment agencies of the Ministry of Community and Social Services with a mandate to provide a variety of community supports to adults with intellectual disabilities.
The project was reviewed and approved by the Queen’s University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board (see Appendix A). Anonymity and confidentiality were assured to all participants. Copies of information sheets and consent forms used are provided in Appendix B, Appendix C, and Appendix D.

Polkinghorne recommends interviewing from 5 to 25 individuals who have experienced the phenomenon. (Polkinghorne, 1989 as cited in Creswell, 2007) I attempted to recruit a minimum of 5 participants for each of the three subgroups in each of the 3 towns or 45 in total.

**Data collection.** Ideally, when one seeks to represent the voices of those whose experiences are under investigation, one relies on in-depth interviews and the analysis of the resulting transcripts’ rich text. However, intellectual disabilities include cognitive and communication difficulties which manifest to different degrees in individuals; some adults are non-verbal and/or achieve a level of functioning only equivalent to that of a young child while others are capable of expressing complex thoughts and are able to assume adult roles. In order to include in the study, adults with intellectual disabilities representing the full range of abilities/disabilities, it was necessary to rely on a multi-pronged approach to data collection. Thus, structured questionnaires were used in addition to interview transcripts.

Interviews, structured and semi-structured, were conducted between November 2006 and April 2007 while I visited the three towns. I spent four days in each community; sometimes commuting back to Kingston, other times renting a room at a local motel. I returned for a fifth day in two of the towns to interview people who were not available during my initial visit. Young adults with intellectual disabilities, their families or workers (caregivers) and the other
community members completed the Neighborhood Sense of Community Scale (Nasar & Julian, 1995) and were interviewed to provide information about their town using questions adapted and expanded from the Social Action Research Project (Health Development Agency, 1999 as cited in Bates and Davis, 2004). These focussed on social cohesion, social capital and social organization. In addition, the young adults with intellectual disabilities completed (by interview) the Belonging subscale of the Quality of Life Instrument Package (Brown, Renwick & Raphael, 1997). Additional quantitative tools were used to characterize the young adults with intellectual disabilities (the Scales of Independent Behaviour –Revised; Bruininks, Woodcock, Weatherman & Hill, 1984), their level of social interaction (Interview Schedule for Social Interaction; Henderson, Byrne & Duncan-Jones, 1981), and the supports they receive (AIMS Interview; Minnes, Buell, Feldman, McColl & McCreary, 2002). The young adults were themselves involved in these more structured interviews if they wished, but in many cases the information was provided principally from their caregivers (parent or paid staff). Copies of the interview guides are appended (Appendix E, Appendix F, and Appendix G). The six published tools embedded in each guide and used in this thesis are described below.

**Neighborhood Sense of Community Scale.** Nasar and Julian (1995) based the Neighborhood Sense of Community Scale on the first published measure aimed at assessing sense of community of place (versus community of interest) which was developed by Glynn (1981 as cited in Nasar & Julian, 1995). The original measure consisted of 60 items which Nasar and Julian reduced to 11 and tested at the neighborhood level. The items which are scored on a 5-point Likert scale (from strongly disagree to strongly agree) reflect four dimensions:
supportive relationships in the community, similarity and relationship patterns of community residents, individual involvement in the community, and community security.

This tool was selected for its ability to measure sense of community at the individual level and to detect differences across towns, as well as for its reliability (Chronbach’s alpha score of .87). The length of the eleven-item scale was practical given the number of other questions being asked.

**Social Action Research Project Questions.** The UK Health Development Agency’s Social Action Research Project is a partnership-based study in two English cities, Nottingham and Salford which used the concept of social capital to help identify the most effective ways of involving local people to support the development of healthy communities and neighbourhoods. The open-ended questions selected for the current study relate to six dimensions of social capital: (1) participation in the local community, (2) reciprocity, (3) feelings of trust and safety, (4) social connections, (5) citizen power, and (6) community perceptions. (Health Development Agency, 2004)

**Quality of Life Instrument Package – Belonging Subscale.** The Belonging subscale of the Quality of Life Instrument Package (Brown, Renwick & Raphael, 1997) captures how an individual “fits in with people and places” physically, socially and at a community level. Two instruments from the package are used; the 18-item Interview (conducted with individuals with intellectual disabilities) and the 12-item Other Person Questionnaire (included in the interview with caregivers).
**Scales of Independent Behaviour –Revised.** The Scales of Independent Behaviour-Revised (SIB-R Short Form) (Bruininks et al., 1984) measures adaptive skills under four domains: motor skills, social interaction skills, communication skills and personal living skills, and the frequency and severity of maladaptive behaviours which it categorizes as internalized, asocial, and externalized. The adaptive skills score provides an age-equivalent score of functional ability (=”developmental age”) and contributes to a support score when combined with the challenging behaviour score. The support score is translated into one of six levels reflecting the intensity of resources needed for improving or maintaining the individual’s functional independence. The SIB-R manual (Bruininks, Woodcock, Weatherman & Hill, 1996) reports that it has good to excellent internal consistency reliability, high test-retest reliability, and good inter-rater reliability.

**Interview Schedule for Social Interaction.** The Interview Schedule for Social Interactions (ISSI) (Henderson, Byrne & Duncan-Jones, 1981) was adapted and used to capture quantitative and qualitative information about the social interactions of both children and adults with intellectual disabilities. This measure assesses what types of relationships (close friends, acquaintances, etc.) are present for the target individual, and that person’s satisfaction with these interactions. Two of its scales are of interest: availability of social interaction, and the adequacy of social interaction.

**AIMS Interview.** The AIMS Interview (Assimilation, Integration, Marginalization, Segregation Scale) is an operationalized version of the Berry (1993) acculturation framework. Nine aspects of integration are rated including: aspects of social and community involvement, access to medical/rehabilitation services, educational services, housing, and spiritual needs.
Research (Minnes et al., 2002) indicates that the *AIMS Interview* used with adults with intellectual disabilities and adults with brain injuries has sound psychometric properties including discriminant and concurrent validity.

**Data management and analysis.** Interviews were audio taped and the full transcript used in the analysis. In two instances, the recording device failed such that I had to rely on notes taken during the interview. Each interview generated on average 11 to 12 pages of transcription for a total of 515 pages (single spaced) of text for qualitative analysis, as described below. Quantitative data from structured interviews were entered in SPSS from which summary statistics were prepared (medians, proportions).

Profiles of the three towns were first developed using census data. Descriptions of the young adults with intellectual disabilities and other study participants were then prepared using results of the structured interviews. The quantitative data obtained from measures of sense of community and belonging were compiled to provide an initial impression of sense of community across the towns and different groups. The interview transcripts were then read several times to obtain an overall feeling for them. Significant statements that pertained directly to the experience of young adults with intellectual disabilities were identified from the transcripts and clusters of meaning from these statements arranged into themes specific to each town. Textual (what young adults with intellectual disabilities experienced) and structural (context or setting that influence how they experience inclusion) descriptions were written for each town using all information collected. The final step was the development of a composite description that presents the ‘essence’ of sense of community experienced by young adults with intellectual disabilities in small town and rural Ontario.
Providing deep descriptions of places and experiences had to be balanced with the requirement to maintain confidentiality. Given the small sizes of the towns and the presence of few identified individuals with intellectual disabilities in the age group of interest (estimated at 10 to 15) residing there, identifying a town could lead to the identification of study participants. In order to protect the anonymity of participants and their towns, the towns are not named and no maps are included. Letters are assigned to each town (A, B and C\textsuperscript{14}) and care is taken not to be too specific in describing them. Similarly, rather than using initials to represent participants, young adults with intellectual disabilities are identified by a sequential number (A_1, A_2,…B_1, B_2,…C_1, C_2,…). Additional coding is used to distinguish the other study participants: STAFF, FAMILY MEMBER, COMMUNITY MEMBER. When a young adult with an intellectual disability was interviewed with a family member present, WITH FAMILY MEMBER is added to the code. For ease of reading, fictitious names are sometimes used when interviewees named individuals in the town.

\textsuperscript{14} While uncustomary, the towns are presented sequentially from C to A. This is the result of having assigned extensive coding to identify respondents before having decided how best to present the results.
Chapter 5: The Selected Towns and Study Participants

The Towns

As per the 2006 Census\(^\text{15}\), all three towns meet the criteria for *Census rural area* (outside places with densities of 400 or more people per square kilometre) and for *rural communities* as defined by the Organization of Economic Co-operation Development (less than 150 persons per square kilometre) since they all have population densities of less than 25. Two meet the criteria of *Rural and small town* in that they are outside the commuting zone of larger urban centres (defined by population of 10,000 or more). (du Plessis, Beshiri, Bollman & Clemenson, 2001)

Beyond their small sizes, these towns have profiles that are distinct from that of the province in a number of ways:

1. the residents are older (median age: ~47 years vs. 39 years),
2. a greater proportion are 3\(^\text{rd}\) generation Canadian or more (~70-80% vs. 46%),
3. their level of education is lower (9 to 17% have some University education vs. 25%),
4. unemployment rates are similar (5 to 6% versus 6%) but participation in the labour force is lower (18 to 59% vs. 67%),
5. there is less linguistic and cultural diversity as measured by statistics provided for mother tongue, immigrants and visible minorities (mother tongue is English: >90% vs. 68%; immigrants: <10% vs. 28%; visible minorities: <3% vs. 23%),

\(^{15}\) http://www12.statcan.ca/census-recensement/2006/dp-pd/prof/92-591/index.cfm?Lang=E accessed 21 February 2009. Data from the 2006 Census is used rather than the more recent 2011 data because the interviews in the three places were conducted between November 2006 and April 2007.
6. there is a more significant presence of residents of aboriginal identity (8 to 25% vs. 2%), and
7. of particular interest to this study, the proportion of residents between 20 and 29 years of age is lower (8 or 9% vs. 13%).

The three towns also differ from each other beyond population density and proximity to urban centers:

- In town ‘A’, the median income and the average value of owned dwellings are near the provincial averages, immigrants are slightly more represented, and the proportion of those of aboriginal identity is highest.
- In town ‘C’, the average value of owned dwellings is significantly lower.
- While the province and the other two towns studied have seen an increase in their population count from 2001 to 2006, town ‘B’ has experienced a decline. It has the lowest proportion of residents from visible minorities and the lowest proportion of residents with some University education. It also has the highest proportion of residents who have no certificate, diploma or degree (that is, who did not complete high school).

**The Participants**

Interviews were completed with 50 individuals across the three towns representing three perspectives of interest: (1) adults with intellectual disabilities, (2) paid and unpaid caregivers living in the same towns, and (3) other community members. In all 17 young adults with intellectual disabilities, 13 caregivers (seven paid and six unpaid), and 20 other community members were interviewed (see Table 4).
Table 4: Study Participants by Town

<table>
<thead>
<tr>
<th>Town</th>
<th># Young</th>
<th># Caregivers**</th>
<th># Other Community Members</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>B</td>
<td>4*</td>
<td>4</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>C</td>
<td>6</td>
<td>3</td>
<td>7</td>
<td>16</td>
</tr>
</tbody>
</table>

(1 family member and 2 paid staff)

(3 family members and 1 paid staff)

(2 family members and 4 paid staff)

TOTAL 17 13 20 50

(6 family members and 7 paid staff)

*a 5th individual was non-verbal; all of his information was provided by a caregiver

**some caregivers responded for more than one young adult and some young adults had more than one caregiver responding. Numbers represent separate individuals interviewed.
The young adults with intellectual disabilities range in age from 20 to 28 years. Eight women and nine men were interviewed. More than half still live with their parents. Over one in four is diagnosed as having an autism spectrum disorder (29%) and over a third suffer from a mental illness (35%). Only two have adaptive skills equivalent to those of 20 year olds, and the levels of support required vary greatly (see Table 5). The young adults with intellectual disabilities interviewed have lived in their respective towns for 4 to 27 years with ten having lived in their town all or all but one year of their life (59%); four having moved to their town as young children (23%) and three being relative newcomers to the town (18%) having moved there less than 12 years earlier.

The caregivers interviewed were predominantly women (11 of 13). Six were mothers of one of the young adults with intellectual disabilities and seven were paid caregivers. Only three of the caregivers interviewed were born in their respective towns (1 for each of the towns studied); two were from other small towns in Ontario, four were from urban centers across Ontario while the others were from other provinces or countries. Seven had lived in their respective towns for more than 20 years. As for the young adults with intellectual disabilities, some of the responding caregivers were relative newcomers to the town having moved there less than 12 years earlier (23%).

The other community members interviewed included police officers, a lawyer, a doctor, local politicians, a high school teacher, church group leaders, directors of community services, business owners, and retirees/community volunteers. Thirteen were women and seven were men. Approximately one third were from the region. Some were from other rural communities
but approximately half were born in urban centers. Five were relative newcomers to their respective towns (<12 years since move; 25%).

Table 5: Characteristics of the Young Adults Interviewed (n=17)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living Arrangement</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With parents</td>
<td>10</td>
<td>59%</td>
</tr>
<tr>
<td>In apartment with or without roommates</td>
<td>5</td>
<td>29%</td>
</tr>
<tr>
<td>In a group home</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td>With a host family</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td><strong>Diagnoses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism spectrum disorder</td>
<td>5</td>
<td>29%</td>
</tr>
<tr>
<td>Mental illness</td>
<td>6</td>
<td>35%</td>
</tr>
<tr>
<td>Behaviour disorder</td>
<td>3</td>
<td>18%</td>
</tr>
<tr>
<td>Seizure disorder</td>
<td>1</td>
<td>6%</td>
</tr>
<tr>
<td><strong>Adaptive Functioning</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age equivalent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 10 years</td>
<td>2</td>
<td>12%</td>
</tr>
<tr>
<td>10 to 14 years</td>
<td>7</td>
<td>41%</td>
</tr>
<tr>
<td>15 to 19 years</td>
<td>6</td>
<td>35%</td>
</tr>
<tr>
<td>20 years or more</td>
<td>2</td>
<td>12%</td>
</tr>
<tr>
<td><strong>Level of support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infrequent or None</td>
<td>9</td>
<td>53%</td>
</tr>
<tr>
<td>Intermittent</td>
<td>3</td>
<td>18%</td>
</tr>
<tr>
<td>Limited</td>
<td>3</td>
<td>18%</td>
</tr>
<tr>
<td>Extensive</td>
<td>2</td>
<td>11%</td>
</tr>
</tbody>
</table>

SIB-R= Scales of Independent Behavior-Revised
In summary, the current study is situated in three small towns that share demographic and socioeconomic features that distinguish them from urban centers. These towns are nevertheless quite distinct from each other. The young adults whose experiences are represented in this study include both men and women, those in their earlier and later 20s, individuals in a broad range of living arrangements, some with and without significant mental health or social impairments, and individuals with varying levels of functioning and corresponding support needs.

The next three chapters describe the evolving understanding of the experience of young adults with intellectual disabilities in rural and small town localities. As shown in the previous chapter, the localities are distinct and the residents from each who were interviewed are diverse and hence expected to provide a wide range of insights and perspectives. In particular, the young adults with intellectual disabilities included reflect the diversity of abilities, co-morbidities and living conditions seen in this population.

As per the hermeneutics cycle depicted in Figure 3, the results are described in the following sequence: perspectives on sense of community, experiences of young adults with intellectual disabilities, and impact of context/place. Each chapter considers similarities and differences across the three named places and concludes with an evolving understanding of social inclusion of young adults with intellectual disabilities in rural settings.

Using data from the various scales completed by the participants, profiles are developed for each town and meanings elaborated. The significant statements and formulated meanings from the interview transcripts are then presented for each place leading to a second reflection on the experience of community in the three named places and generally.
Chapter 6: Experiences of Young Adults with Intellectual Disabilities

– A Quantitative Analysis

Having introduced the small town communities selected and the study participants, this first of three results chapters answering the question “What is it like to be a young adult with an intellectual disability living in a small town in Ontario at the start of the 21\textsuperscript{st} century?” uses quantitative measures to describe their sense of community, their satisfaction with belonging, and their views on the availability and adequacy of social interaction. A qualitative analysis based on interview data follows in Chapter 7.

Perspectives on Sense of Community

The scores on the Sense of Community Scale completed by all participants in each town (young adults with intellectual disabilities, their caregivers, and other community members), suggest that sense of community is very strong in all towns.\textsuperscript{16} The average scores for each town (combining responses from all respondents) were 4.3 (range: 3.1 to 4.7), 4.4 (range: 3.6 to 5.0) and 4.2 (range: 2.9 to 4.8) in towns C, B and A, respectively, out of a maximum possible score of 5.

The average score on the sense of community scale as reported by young adults with intellectual disabilities also suggests a very strong sense of community among these participants specifically (median: 4, range: 2.9 to 4.6). The item scored the lowest by young adults with intellectual disabilities relates to friends being part of their everyday activities. Conversely, high

\textsuperscript{16} In a study of suburban communities, Nasar (2003) reported mean scores of 3.6 and 3.7 which he referred to as moderately strong sense of community. Similarly, Lund (2002) reported scores of 3.48 and 3.70 in two urban neighborhoods. No studies using the scale in rural communities were found.
ratings were obtained for “(e) people here know they can get help from others in the town if they
are in trouble”, and “(k) if I had an emergency, even people I do not know in this town would be
willing to help”. See Table 6.
Table 6: Scores on Sense of Community Scale - Young Adults with Intellectual Disabilities (n=17)

<table>
<thead>
<tr>
<th>Item</th>
<th>Median Score</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I am quite similar to most people who live here.</td>
<td>4</td>
<td>1-5</td>
</tr>
<tr>
<td>b. If I feel like talking, I can generally find someone in this town to talk to right away.</td>
<td>4</td>
<td>3-5</td>
</tr>
<tr>
<td>c. I DON’T care whether this town does well. (R)</td>
<td>4</td>
<td>1-5</td>
</tr>
<tr>
<td>d. The police in this town are generally friendly.</td>
<td>4</td>
<td>1-5</td>
</tr>
<tr>
<td>e. People here know they can get help from others in the town if they are in trouble.</td>
<td>5</td>
<td>1-5</td>
</tr>
<tr>
<td>f. My friends in this town are part of my everyday activities.</td>
<td>3</td>
<td>1-5</td>
</tr>
<tr>
<td>g. If I am upset about something personal, there is NO ONE in this town to whom I can turn. (R)</td>
<td>4</td>
<td>1-5</td>
</tr>
<tr>
<td>h. I have NO friends in this town on whom I can depend. (R)</td>
<td>4</td>
<td>1-5</td>
</tr>
<tr>
<td>i. If there were a serious problem in this town, the people here could get together to solve it.</td>
<td>4</td>
<td>1-5</td>
</tr>
<tr>
<td>j. If someone does something good in this town; that makes me feel good.</td>
<td>4</td>
<td>3-5</td>
</tr>
<tr>
<td>k. If I had an emergency, even people I do not know in this town would be willing to help.</td>
<td>5</td>
<td>3-5</td>
</tr>
<tr>
<td>TOTAL (after accounting for reverse scoring)</td>
<td>4</td>
<td>2.9-4.6</td>
</tr>
</tbody>
</table>

(R) = reverse scored
The sense of community reported by young adults with intellectual disabilities was not uniform across the three towns as reflected in the range of total scores. The lowest rated item for each town provides an indication of the factor influencing lower ratings in each town for this group of respondents. As shown in Table 7, the young adults with intellectual disabilities who responded across the three towns are affected differently by various elements contributing to sense of community. In Town C, the perception that police are not generally friendly appears to be a significant factor while in Town B friends not being part of one’s everyday activities, and in Town A not perceiving oneself as similar to most people in the community have a greater impact.

Table 7: Sense of Community Scale Scores - Young Adults with Intellectual Disabilities across three Towns

<table>
<thead>
<tr>
<th></th>
<th>Town C</th>
<th>Town B</th>
<th>Town A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total score</td>
<td>3.1 to 4.6</td>
<td>4.1 to 4.6</td>
<td>2.9 to 4.6</td>
</tr>
<tr>
<td>range</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lowest rated</td>
<td>(d) The police in this town are generally friendly.</td>
<td>(f) My friends in this town are part of my everyday activities.</td>
<td>(a) I am quite similar to most people who live here.</td>
</tr>
</tbody>
</table>

Sense of community was experienced differently by young adults with intellectual disabilities, their caregivers, and other community members. See Figure 4. Being a service recipient appears to have an impact on the young adults with intellectual disabilities’ sense of community as the two items they rated above 4 both relate to resource supports in the town. In
contrast, their caregivers and other community members gave items such as having friends to depend on and friends to talk to, as well as caring about the town their highest ratings. In some ways, the caregivers are more similar in their ratings to the young adults with intellectual disabilities (items related to services) and in other ways (social connections and interest in the town’s success) they are more similar to other community members.
Figure 4: Median scores on Sense of Community scale items and overall by respondent group (3 towns combined; n=50)

Legend:

a. I am quite similar to most people who live here.
b. If I feel like talking, I can generally find someone in this town to talk to right away.
c. I DON’T care whether this town does well. (R)
d. The police in this town are generally friendly.
e. People here know they can get help from others in the town if they are in trouble.
f. My friends in this town are part of my everyday activities.
g. If I am upset about something personal, there is NO ONE in this town to whom I can turn. (R)
h. I have NO friends in this town on whom I can depend. (R)
i. If there were a serious problem in this town, the people here could get together to solve it.
j. If someone does something good in this town; that makes me feel good.
k. If I had an emergency, even people I do not know in this town would be willing to help.

1= lower Sense of Community; 5=higher Sense of Community
In summary, the use of the *Sense of Community Scale* to tap into the experience of community of young adults with intellectual disabilities revealed variations among individuals within and across the three towns suggesting that individual factors as well as characteristics of the town influence sense of community. Furthermore, the scores suggest the experience or perception of friendship and reciprocity may be quite different for adults with intellectual disabilities. These preliminary findings will be examined further as other data collected are examined.

**Satisfaction with Belonging**

Using the *Belonging Subscale*, the young adults with intellectual disabilities were asked how important community belonging was to them; namely going to school, working and going to places in their town. A large proportion indicated that for them working was very important (83%). Similarly, 72% said going to places in their town was very important to them. For a few, being able to continue to learn through college or other training programs was important (22%). For one individual, community participation was not important. As shown in Figure 5, satisfaction with one’s level of community belonging among young adults with intellectual disabilities varies not only across individuals but it is generally higher in Town A.

The young adults were also asked how important social belonging was to them; this included their family, friends and having a husband/wife/partner. Almost all (89%) rated their family and having friends as very important. A smaller group indicated that having a partner was very important to them (61%).
In terms of physical belonging, the young adults were asked how important their home, space for privacy and their neighbourhood/residential area were to them. As a group, they place less importance on these aspects of belonging including the specific neighbourhood in which they live than on community and social belonging.

**Social Interaction**

The young adults with intellectual disabilities have unique patterns of social interactions (as measured by the *Interview Schedule for Social Interaction*) with some in each town having minimal to no opportunities for social interaction (score < 2) and others in each town having many opportunities (score > 4). In contrast, adequacy of social interaction is rated low (score < 4) by all in Town C, 71% in Town A, and 40% in Town B (see Figures 6 and 7).
Figure 6: Availability of Social Interaction Scores for Each Young Adult with an Intellectual Disability by Town (Towns denoted by A, B and C; each bar represents an adult with ID)

Figure 7: Adequacy of Social Interaction Scores for Each Young Adult with an Intellectual Disability by Town (Towns denoted by A, B and C; each bar represents an adult with ID)

Taken together, the data from the *Belonging Subscale* and the *Interview Schedule for Social Interaction* indicate a lack of congruence between reported satisfaction with community belonging and availability or adequacy of social interaction at the individual level. Some
individuals report being very satisfied with community belonging yet indicate few opportunities for social interaction (C3, A1, A2 and A3). In the case of C3 and A2, social interaction is felt to be completely inadequate. A1 provides an example of an individual who reports high satisfaction with community belonging despite having few opportunities for social interaction which are deemed adequate. These discrepancies point to the need to consider individual differences in desired levels of social interaction.

Combining these results with the findings from the *Sense of Community Scale* sheds some light into elements that may contribute more to satisfaction with community belonging than social interactions for young adults with intellectual disabilities. As noted, young adults with intellectual disabilities are more likely to score higher on elements of reciprocity (having a sense that the town is there for those in need) than on items related to intimate contact with others.

A closer examination of scores for individuals in Town A suggests that community level influences may also be important. Since these young adults tend not to see themselves as similar to other community members (see Table 7), it is possible that they report satisfaction with community belonging because they feel they belong to a sub-community; namely that of persons with intellectual disabilities and their support workers.

Applying Liepins' framework to these emerging understandings of the experiences of young adults with intellectual disabilities in the small town and rural communities, highlights the relative importance of some practices (reciprocity) versus others (social interaction) to the creation of meanings (sense of community and satisfaction with community belonging). It also
begs one to consider the extent to which the lack of importance (meaning) attributed to college education or training opportunities by the young adults interviewed may result from lack of programs (spaces and structures) and/or lack of expectations (meanings) or effort (practices) on their part or that of others. Finally, the finding that a sense of similarity is also relevant suggests that elements of structure (socio-demographic profile of the town) also need consideration.
Chapter 7: Experiences of Young Adults with Intellectual Disabilities
– A Qualitative Analysis

The interview transcripts for each town were read and re-read several times to identify significant statements related to the experience of young adults with intellectual disabilities. The statements represent different voices; that of young adults themselves, their caregivers and other community members. Together, they form a text to explore contexts and situations that typically influence the experience of community for young adults with intellectual disabilities in each small town. The next section relies on a series of tables for each town in which significant statements are presented along with related formulated meanings (found in Appendix H). A summary is provided for each town along with a selection of supporting statements.

What is the Experience of Young Adults with Intellectual Disabilities in Each Community?

The interview transcripts revealed unique and common experiences for young adults with intellectual disabilities in their respective small town and rural communities. Citing the various members, insights for each town are presented in this section.

**Town C**\(^\text{17}\). In this town, young adults with intellectual disabilities express ambivalence about living in the town; it offers a peaceful quiet setting but there is a desire for more opportunities and social interaction.

It’s not big. There isn’t that much traffic or anything....

*What do you like about where you live?*

---

\(^{17}\) see Tables H-1a, H-1b and H-1c for all significant statements and formulated meanings.
It’s on a lake. It’s quiet.

*Do you think people enjoy living here?*

Yeah. Because it’s like probably a quiet town. And there’s lots of things to do.

*Do you enjoy living here?* Yeah

*Is there another place you’d rather live?*

I’d rather live in a city because there’s more opportunities in there.

*Do you think you might move to a city sometime?* Yeah, I plan on it. C_2

*What do you like about where you live?*

It’s peaceful and quiet.

*What do you not like about where you live?*

Just nobody to visit….It’s a pretty quiet town…just one quiet town…with nothing to do.

*Do you think people enjoy living here?*

No. Just a little hick town. Too quiet. It’s okay for the old, old guys like my dad and mom. But young people probably like chilling out in [the city] or something. I never made a change, but I want to leave. C_5

*Do you think people enjoy living here?*

Yeah. It’s peaceful.

*Do you enjoy living here?*

No. I can’t wait to get away from this town….I wish I was still living in [the city]. I used to … and then I moved back here and I am stuck here again. Most of my friends live in [the city]; the ones I went to [high school] with….There’s not much to do. I call it the Ghost Town ‘cause it’s so boring. C_4

They report a loss of contact with friends after high school leading to a sense of being left behind.

I have a couple [friends] and the rest are all far away…They moved, to [the city]…after they graduated. C_1

But now all my friends are gone. …they all moved out because they got jobs. C_3

*How often do you spend time with your friends?*

Uh, not as much as usual. Not since school. C_2

Yet, there is a perception that if young adults with intellectual disabilities are staying it is by choice.
I think boredom is a big thing sometimes...But I think in general, it’s not too bad. Umm, the reason I say that is that, uh, people do have a choice. I mean, if people want to move somewhere, then they’re free to move. We don’t keep them here. And if they did want to move to [this city] or [that city], then I would think that they would go. A lot of people have been here now for a long time, so they have those friends and they have those connections. So they see it as their home and this is where they want to be. Like everyone else who’s here, despite the complaints that nothing’s going on. C_STAFF_1

While there are very few organized social and recreational activities for young adults, the proximity of extended family contributes to a sense of belonging in the community.

I feel like I belong here. I got a lot of family that lives here. I’m related to pretty much all of [the town]. C_3

For some, social interactions outside the family are stressful.

*Re: sons with intellectual disabilities feeling part of the local area:* They stay to themselves. They’d rather do things on their own.

*Re: participation in day programs:* They don’t like being with a bunch of people.

*Re: volunteering:* They don’t want to leave the house. C_FAMILY MEMBER_1

Deep friendships are not common, but young adults with intellectual disabilities have many acquaintances; they are known and they help others in the town.

My sense is that we just accept them because we tend to see them every day, especially those that are working with [the agency]. They have the drop-in centre. They have a hot lunch, I think it’s once a month. So there’s a number that I’m used to seeing. My children are used to seeing them. They know them. They talk to them. C_COMMUNITY MEMBER_1

I think they’re quite accepted and I think part of it is that they’re visible. That’s something that struck me right away is the visibility. I think because of the proximity of, especially, the location of [agency] office. So the clientele is right out in the urban core –whatever urban core we have- they’re right here. So they’re very highly visible. And I think in like of that, the general population, you know, is quite accepting and warm and, from what I’ve seen, you know, very accommodating to maybe some of their special unique characters and things like that. C_COMMUNITY MEMBER_3
There’s a gentleman, [Paul], comes and does the shoveling and clears off the walkways. And I see him walking daily. We have another fellow who, in the summer, we see him with his fishing pole, and he walks around. There’s another gentleman that I’ve known over the years, and, yeah, I love to see him at all the annual general meetings for all the organizations, and this and that. You know, they’ve been out and about, and I’ve come to recognize them. C_COMMUNITY MEMBER_1

Community involvement is easier for those who are seen as similar.

I think the population that we support here, because most of them are fairly high functioning, most of them don’t have a lot of very obvious, umm, disabilities or sort of, I guess, violent or socially unacceptable behaviours, you know, that are right out there. I think, uh, I think that makes a bit of a difference for the people trying to get involved. C_STAFF_1

Social segregation occurs and there is recognition that the local developmental service agency may play a part in creating it.

They (young adults with intellectual disabilities) have a close group amongst themselves. The [agency] supports and helps. They go for out-trips and things like that. C_COMMUNITY MEMBER_7

Many young adults with intellectual disabilities express a desire for paid employment - “[most people] sit around the house and do housework, hoping they can get a job” C_6 - but no concrete planning or preparation is undertaken for employment. Caregivers and community members acknowledge that employment opportunities are very limited for adults with intellectual disabilities.

Re: employment
I can’t say that I’ve seen them in any stores. Certainly doing lawn maintenance. There’s the [town] lawn service and that sort of thing.”…”I think the opportunities are really limited, because they’re competing with adults who are fully capable and who are having difficulty finding work. So I think it’s very difficult for them to find employment. It’s difficult for anyone to find employment in this area. C_COMMUNITY MEMBER_1

Are there jobs for them (adults with ID)?
Not many. But there’s not many jobs for a lot of the people, even without disabilities…we’re not well endowed with jobs. It’s a challenge for everyone…

C_COMMUNITY MEMBER_3

Employers and the community in general are supportive of those who want and can work but the scarcity of opportunities in the town means that they tend to be given volunteer positions.

So some people have managed to get a niche that they can work in, and satisfy, and certainly the community is willing to support them as they can.

C_COMMUNITY MEMBER_7

There’s an attempt to accommodate. I could think of two or three that have held kind of protected type jobs, you know, around the grocery store, gathering up carts outside and shoveling the store, putting salt down on the ice. That kind of thing. And I think, again, because of it’s a small community, everybody knows everybody. Everybody knows what everybody’s limitations are and what people’s capabilities are too. C_COMMUNITY MEMBER_1

In Town C, the experience of young adults with intellectual disabilities is not dissimilar to that in many rural communities. They face unemployment and they experience the loss of age peers who move away. Their sense of community is enhanced by their similarity to others and the presence of extended family members.

Town B\textsuperscript{18}. In this town, several young adults chose to be interviewed with their mothers and in one case where the young adult could not be interviewed, only the mother participated. To highlight the fact that the information obtained through these interviews is not solely from the perspective of the young adults with intellectual disabilities, the presentation of results from the analysis of interview transcripts clearly indicates where the views expressed may reflect the mothers’ perspectives.

\textsuperscript{18} See Tables H-2a and H-2b for all significant statements and formulated meanings.
In Town B, young adults with intellectual disabilities and their mothers report highly variable experiences of being known, accepted and included. These are enhanced by the family’s prominence in the community, as well as the social skills of the young adult with an intellectual disability and his/her parents.

(*mother*) People are extremely wonderful with you (mother says to son), aren’t they? Everybody knows (name of son)! And there isn’t a single person who wouldn’t go by and give him a high five.” (*son adds*) Or a hug. (*mother resumes*) Yeah, he gets lots of hugs, you betcha! For [name of son], it’s really a wonderful community, an accepting community for him. … I’m not sure that they (*other persons with ID*) have the integrated acceptance that [son’s name] has. [Son’s name] is extremely integrated. Goes to all the local hockey games and everybody includes him in their activities. He has more inclusion than some of the others who have more social life with just each other. But [son’s name] has broken through those boundaries almost. He’s very social. He loves to talk. He’s quite open and honest. I always pushed for inclusion. I always told him he could do things. … I feel extremely, myself - as a mother of a challenged adult, I feel personally extremely grateful that he has the acceptance in the community that he does. Because I have seen examples of it not working so well … I am extremely grateful that [name of son] is as well accepted in this community as he is. *B_WITH FAMILY MEMBER_3* (highly social young man with a visible disability whose family is very involved in the community)

(*mother*) Just from our personal experience, I don’t think there’s enough understanding, awareness of people with disabilities. I think just due to lack of exposure… I know even trying to find [daughter’s name] a co-op in high school. (*daughter adds*) That was quite the challenge. (*mother resumes*) We found at the time… not very many employers who were really open to having someone with a disability doing a co-op or with possible future employment. It was very limited; I was sort of surprised being a smaller community.… We don’t find them that willing to include. *B_WITH FAMILY MEMBER_2* (young woman with a less visible disability whose family recently moved to the town from a larger center and who describes herself and her family as ‘homebodies’)

There is a sense that the invisibility of the disability hinders inclusion as it leads to inadequate supports which is felt as discrimination.

(*mother*) Even with school, she was always in the catch twenty-two. She didn’t fit here, and she didn’t fit here, and it’s been very difficult. (*daughter adds*) It’s been like that for my whole life. (*mother resumes*) Yeah, and it’s a very invisible
disability, which sometimes is a positive, but not always. B_WITH FAMILY MEMBER_2

In speaking about the uniqueness of the town, young adults with intellectual disabilities and their mothers tend to point to contrasts with larger centers; both positive (greater safety) and negative (fewer opportunities for social and educational pursuits).

(mother) Coming from the city, I used to have terrors thinking that young people would give him drugs or hurt him or want to fight with him because he was a little gullible. You know, try and get him in trouble? … He’s extremely lucky to be in a community where a lot of the time things are safe and there isn’t the same kind of gangster psychology behind the groups of kids like there is in the city. B_WITH FAMILY MEMBER_3

Re: having moved to the town from a larger center
(mother) The part that I find hard as a parent is having two children with special needs. Sometimes I question whether I made the right decision for them. I know they’re happy in (name of town) because of nature….They enjoy a lot that’s here, but socially-wise and our school system, compared to what they would have had available to them in a city, it’s greatly lacking. B_WITH FAMILY MEMBER_2

Affordable housing is limited but some parents are finding solutions.

Why do you live at home?
To be close to my family. (mother adds) He actually wants his own apartment, to live somewhere else. But he doesn’t make enough money, really to afford a $600 a month apartment. His pension is $700. So right now, there isn’t really anything he could afford. …We bought a house in town with a basement apartment, a potential basement apartment sort of started in there. We had our father-in-law living there. [name of son] is supposed to move in the spring. …I realized that the housing situation in this particular community was very grave. There wasn’t any opportunities for even a challenged person or a senior or a single or anything; we’re very limited with housing. B_WITH FAMILY MEMBER_3

Why do you live at home?
Because of the cost….And, I get along good with my parents. We’re very similar, so we don’t really have a problem. That’s basically it. I’m happy there. (mother adds) We purchased that house basically because of the way that the lower level was. We thought that would be good for [daughter’s name]. It’s a walk-out level that she can basically have the run of, other than she’d have to share the kitchen and laundry facilities. B_WITH FAMILY MEMBER_2
The transition from school often means loss of connectedness as well as day activities.

*Re: leaving school (mother)*

At first, he found that it was extremely difficult. He had bonded with so many of the students. … He had a really hard time trying to figure out what to do with his whole day when he didn’t get up and have to go to school. It was a whole social issue there. There was no contact with other kids on a regular basis. Everybody at the [agency] was a tad older. So he didn’t really have as many peer times, you know, for social or projects or trips or different things….After a while, that worked out alright. But I had to try to make him realize that ‘You are no longer in school. You have to move on to other kinds of activities for your day.’ …It was hard for him to make the transition. B_WITH FAMILY MEMBER_3

Some young adults with intellectual disabilities report using the internet to make and maintain long distance relationships while others connect with others through civic engagement.

I do have friends who live far away, but I don’t go see them. I talk to them...phone or internet. …

*Re: siblings*

I don’t see them often because they’re working. But I talk to them on msn. B_5

*Re: friends who live outside the area*

Well, I’ve visited them, but I’ve met them on the internet. …I met this one guy face to face who’s been on the youth exchange one year and then I met his friend on the internet, on msn. B_1

*(Mother about her son’s involvement in advocacy)*

His focus is more like for the challenged folks and for the things that they have to cope with. So those are more his advocacy focuses. But yes, he will participate in, you know, election committees. And he was part of a rally there for them. Or he will participate in church functions. He likes to go to church every Sunday. And if they have their fundraising or doing something like collecting for groups and donations. *(son adds)*'we are in the parade as well'. B_WITH FAMILY MEMBER_3

*Do you know of individuals with intellectual disabilities who are part of the local area?*

Yes, a lot of them get this through volunteering. [Daniel] goes to the Fire Department and has coffee with the men there. They even gave him a jacket. He is part of it. B_COMMUNITY MEMBER_1
The social benefits of employment are recognized by young adults with intellectual
disabilities and their mothers.

*Do you think it is important for people to work?*
*Yes.*
*Why?*
Because it makes you happy. And you’re not sitting at home and doing nothing.
And you’re not bored and depressed like me some days. It’s really hard. Plus you
get to have the experience of working with others, of getting into relationships
with your peers at work. B_WITH FAMILY MEMBER_2

However, paid employment opportunities are scarce for all

* (mother) I think most of what they do is volunteer….Like I said, there’s not even
a lot of work for even the regular person, let alone a special needs person.
B_FAMILY MEMBER_4

and employment is seen as something that comes along rather than something adults with
intellectual disabilities should plan for.

Someday, I want to go to school and get my early childhood education.
*When do you think that will be?*
I am not sure.
*Are you working on that?*
Kind of; it’s just something in my head. B_1

* (mother) I always said that [son’s name] could be the perfect Walmart greeter.
And there is the potential of a Walmart coming here, and he wants that job badly.
So if something came along, he would be able to work full-time and support
himself. B_WITH FAMILY MEMBER_3

The cost of getting to work is a barrier to employment for some.

*Do you have a job?*
Actually, no, because of transportation issues.
*Do you live in town or outside of town?*
We’re about six kilometers south. I was offered a job at [name of store]. It cost
$25 round-trip for people with disabilities, $25! A taxi from where I live? $20
they were going to charge me every day. So then I’d be working for peanuts. I’d
like to make a little bit too, because I’ve worked hard for that.
(mother later explained) Even with getting her into work without us having to drive her. . . . It’s an on-call basis, to start off with, you know, which hopefully would work into something more scheduled. That’s not really something we felt was fair for us…For her to have to use the transit for the disabled, $25 round trip. So we sat down and worked it out with what she’s allowed to earn extra over and above her pension. It would end up costing her money. B_WITH FAMILY MEMBER_2

The local developmental service agency is seen as fostering a sense of community for those it supports.

(mother) I know that we have some really incredible special needs people that come to this center (agency). There’s a few of them that just absolutely, well, they all have a little piece of my heart, so….But there’s a couple of them that are special to me. And I’ve only met them since I’ve come here. They all know [son’s name], and if I’m downtown shopping, they come up to me and talk to me. And say hello to [son’s name]. It’s just kind of nice. B_FAMILY MEMBER_4

Many adults with intellectual disabilities are reliant on the agency to provide a patchwork of day activities; others feel unsupported or wish the agency could do more.

What are you doing now instead of going to school?
I’m working with [name of the agency].
Are you here every day?
Other than Wednesday, I am only here at night on Wednesdays.
What do you do here on Wednesdays?
I clean.
And the rest of the time, when you come, what do you do?
I do the mail run for them and then I also do cleaning every day, but Wednesdays is the later one.
What time do you come in?
One o’clock.
How long do you stay when you come to do the mail run?
It’s usually between half an hour to an hour.
And the cleaning, how long does that take?
Tuesdays and Thursdays it only takes half an hour…Monday, Wednesday, Friday, it takes two hours.
Do you do that alone or with someone else?
I do it by myself.
What do you do in the mornings?
Nothing.
And the rest of the afternoon, when you come here, do you have other things that you do after?
“Monday and Wednesdays after the mail run, I used to go to [hamlet] and go to fitness.
What do you do on week-ends?
Nothing. B_5

Re: case management (mother)
There’s nothing in our situation. I really feel like I’m sort of left on my own.
Re: respite care and other residential supports
That’s apparently there, but we’re responsible as guardians or parents to arrange
that on our own. And being new in a community….And to the extent that I would
like to know people to put, you know, to have in charge in that way….That’s been
very difficult. It tried it once, and did not have a good experience, so I just don’t
go there. We provide as a family and that’s it. B_WITH FAMILY MEMBER_2

Social activities, even those organized by the agency, are not for everyone.

(mother) This center (referring to the agency) tries to do things for them, like get
out. They do day trips and different things certain times of the year. Umm, [son’s
name] sometimes can manage some of them, but a lot of them, he doesn’t really
qualify, because his needs are too high. So he’s gone to the odd dance, but not a
lot. Umm, because he would have to be pushed around in a wheelchair to go
shopping. B_FAMILY MEMBER_4

It would be nice to have people my own age to hang out with. And to have fun
with.” (mother adds) The one thing [name of daughter] has found is a lot of things
that are provided, which is basically through [name of the agency], she’s higher
functioning. So it’s just not a fit. B_WITH FAMILY MEMBER_2

Community members express divergent views on the extent to which inclusion of persons
with intellectual disabilities occurs in their town. Some speak with pride of how their town is a
place where individuals with intellectual disabilities are known by name. Others perceive the
community as tolerant but not engaged.

They (individuals with intellectual disabilities)’re all known, you know, and most
of them by name, umm, which is fine. It’s great, actually. B_COMMUNITY
MEMBER_4

Tell me about [name of town]? What makes it special, different from other
places?
I think the nice thing about our community is the care for the special needs. And that they are included in the community. And that everyone looks out for them. And I think that’s a beautiful thing about our community.

We - the community needs to become more involved with people with intellectual disabilities. There’s no question about that.

Community members are aware that many individuals were brought to the town to be supported by the local developmental service agency.

I’m actually trying to think if there are any (young adults with ID) local, locally born; right at the moment. I don’t think so. So many of them have lived here for so long, that – and don’t forget that some of them came from institutions – umm, so there isn’t another place that’s home, you know?

Many of these young people (with intellectual disabilities) are not from here. They arrived and because of the local [agency]. It’s a business, and that’s their business, and so they need the clients to get the grants to run the organization…So they have taken enough people into the community to justify what’s going on. And they do a good job, they do a good job. But as far as introducing those people to the community, as far as doing that OUT there to the community, no that doesn’t happen.

While the work of the local developmental service agency is appreciated, there is a sense that it hinders social inclusion of the individuals it supports; it makes the needs of individuals invisible to the community.

*As far as recreation goes, do they take part in what you consider the same sort of activities in an integrated way with other residents?*

No, no I don’t see that. I see them very much having their own programs that are more programs which are organized for them. If I could ever make a suggestion to the [name of agency], it would be – open those programs and invite the community in. Then, maybe you could go the other way also. On the other hand, I noticed recently at an all candidates night, that two of the clients (adults with intellectual disabilities) were there….Often at an artistic performance, particularly at a musical performance, you’ll see one or two that love music are there. But not generally speaking.
As long as you have an organization like [name of agency], which in some cases is between the public and their clients, the public really doesn’t know (what individuals need, how to help). And I’m not saying [name of agency]...it’s a very difficult place to be in; it’s a difficult thing to comment on. But as long as you buffer, then how is the community supposed to know that there is a need? Because the need is always expressed in terms of [name of agency]: ‘We need members, we need money, we need whatever.’ Not ‘[Jim] needs…’ but ‘[name of agency] needs’. There’s no appreciating or knowing what those people need, unless you, on an individual basis, and you’re at a restaurant and young [Rachel] who walks with a walker is having trouble going through the door, you help. But you have no concept of what [Rachel]’s other needs might be. B_COMMUNITY MEMBER_3

There is a lack of awareness of how to engage with persons with intellectual disabilities.

But most of the people in the community haven’t got the slightest idea of how (to engage with persons with intellectual disabilities), and the answer would be, well, get on the board of [name of agency]. That’s not really where a lot of people want to be, you know? I mean, it would be so simple to do things to bring the two groups together. Not that they’re disparate, it’s just they’re invisible, you know? They ARE invisible. B_COMMUNITY MEMBER_3

Stereotypes, prejudice and discrimination are seen and expressed.

Here people kind of have a mindset and a way of thinking. So they might be more apt to label someone with an intellectual disability as being…I don’t know if it’s just lack of saying something properly, but they’d be more apt to, say, use the term ‘they’re retarded’, or ‘they’re handicapped’ as opposed to talking in terms of intellectual or developmental disabilities….And I don’t know if it’s a case of them being, like, using a negative connotation or if that’s kind of the only word they know for it. B_COMMUNITY MEMBER_5

RE: opportunities for employment for your adults with ID
I’ve see them...a few...I’ve see them many times in restaurants. And I’m not convinced that’s the place. And I say this not critically but many times we rush and rush and rush. And we have to have more teaching and understanding about them, I think, if they’re to be working in restaurants and things….Candy stripers yes, or helping. And like [Liam] does, at the door. You know, as a welcomer at the door. He’ll often be at the door at [the local theatre]. And they like that. …They’re ‘people’ people. They’re social. So, it’s almost your welcoming things that I see as a strength that they have….I just, I think I see them as door people. Umm, because often their coordination and whatnot is a bit difficult at times and so therefore a standing position where they can just speak and welcome. B_COMMUNITY MEMBER_2
The interviews in Town B revealed significant diversity in needs, expectations and experiences among young adults with intellectual disabilities. Elements associated with the isolation of rural communities are apparent; transportation issues are raised and the internet is increasingly being used to maintain connections. The role of the Developmental Service agency in bringing individuals with intellectual disabilities to the town and in creating a community for the individuals they support and their families is highlighted.

Town A. In this town, young adults with intellectual disabilities and their mothers report that being known is an important feature of living in this town but, for some, the disability label limits being known.

(mother) Yeah, everybody in [hamlet] knows [daughter’s name], so…They’re really, they make a fuss over her. A_WITH FAMILY MEMBER_1

If I had a disability, I wouldn’t want to live here. I shouldn’t say that. If I knew, like knowing what I know when seeing what I see, I wouldn’t want to be someone with a disability living here because it’s really hard to sort of grow as an individual and as a person. Because people in the community see you as a disabled person instead of, you know, that tall girl with the blonde hair, you know, who likes horses. A_FAMILY MEMBER_2

Paid caregivers report that those who live independently are more likely to be recognized as they access the community more; there is a sense that with recognition comes respect and concern by reducing perceptions of difference.

I would say people with intellectual disabilities are treated well if they’re known in the community. So that would be people who live independently, who live, umm, who are independent, that people in the community would see often. Other people that receive support from us, umm, that don’t have as much access to the

19 See Tables H-3a, H-3b and H-3c for all significant statements and formulated meanings.
community or have higher needs are maybe not, they’re not as well-respected. They’re not, you know, if they were to go to Tim Horton’s and, receiving support from myself, the clerk would likely address me before the person that I’m there until I would say, ‘Tell the person, you know, tell the lady what you want’ I would always get addressed first. So, but I mean they’re not, I, they’re treated well beyond that but they’re not given a lot of respect, I would say, unless they’re independent and they’re in the community all the time. So a lot of it (re: how people with ID are treated) depends how the town gets to know that person, sort of their reputation; and their family too. Umm, if their family has a decent name…again, small town stuff, a lot of it goes with name.

However, some note that independence (less obviously disabled) leads to frequently being seen which combined with conformity leads to acceptance. Those more dependent are less likely to be seen and are typically seen in groups (“always with their own”) or with staff which amplifies the perception of difference.

There’s a gentleman… [Francis]…and, uh, he’s still alive….He grew up in [hamlet]. And [hamlet] community accepted him very well and looked out for him. He bicycles everywhere and sells tickets on every raffle going. And he has been accepted very well in the community, extremely well. Taken under the wing of the [local] hockey team and does their equipment managing. And he, he is an example of someone who has been very well-accepted in the community…I think somehow the chemistry came together. The right people were there. [Francis] has a very out-going personality. … Like [Francis] just loves people so he’s out all the time. And he goes to the coffee shop with the guys and he does everything everybody in our community who wants to be socially busy does. … [Francis] lives right in the village. And he can bicycle anywhere. We have people with intellectual disabilities who live out in the country. And unless somebody’s going to drive you, you’re not able to do that. I mean, if [Francis] wants to go and have coffee with the guys, he walks or hops on his bike and does it. But if you live five or six kilometers out in the country and you want to have coffee with the guys and the gals in here at Tim Horton’s and you don’t drive, it’s not likely going to happen. And so I think transportation might be a factor on that because I’m thinking of a lady who lived out in the country and unless her relatives drive her in, for any event, she isn’t going to get in. I think for the most part, they’re very well treated. Umm, last year, we had a fellow die. His name was [Brian]. And, umm, [Brian] was, umm, a former, a person from an institution. I knew him when he was institutionalized and then he
lived in the community. And he died… I can’t just exactly remember. But an overflow at his funeral, and umm he was well-loved and well-liked, and I know that the place where my daughter works… He was in there every day, and you know, he was part of their work community and their social community, and umm they were devastated when he died. And we’ve had similar other things… another fellow who was very involved in the community and fund-raising and things like that – [Donald]. And again he died, you know, it was just like an outpouring of community sympathy. And it doesn’t just happen when people die, of course. When you go to Tim Horton’s there’s often a group of people there who are intellectually delayed. And they’re not treated any differently than anyone else that I can observe. For the most part, I think this community does very well. I think that maybe the problem comes with people who are more obviously disabled, people with, umm, kind of aberrant behaviours. That’s a little harder for people to cope with, but people cope. A_COMMUNITY_MEMBER_2

There is a recognition that there are variations in the ability of each person, whether disabled or not, to be accepted and be accepting.

A perfect example (of people with intellectual disabilities being part of the community) is one of the folks that we supported passed away. And half of the businesses in town were closed that day to attend his funeral. So the church was packed. The outside was packed; people standing outside. And that was somebody we supported who was definitely part of the community. A_STAFF_3

…and sometimes they’re respected, sometimes they’re not. I guess it depends on the person… I think it depends on how the person (with intellectual disabilities) presents themselves. Or it depends on the people in the community because some people are not accepting. A_STAFF_4

Paid caregivers observe discomfort on the part of many community members when interacting with adults with intellectual disabilities.

There are people that don’t appreciate having people with disabilities around – ‘the kids’ as they call them… You’ll be at [name of store] and, uh, you know, helping somebody get some change together. The one time I was helping someone drop off a roll of film to get developed. And the lady at the cash looks at me and says ‘what’s his address?’ And I looked at him and said ‘what’s your address?’ And he told her. She looked at me and said ‘what’s his phone number?’ I said ‘what’s your phone number?’ And he told her… and not to suggest that she didn’t want him in the community, but may just not be sure how to interact or engage, engage him. A_STAFF_2
I think if I was to fall down and hurt myself, I would get more reaction maybe than say if somebody fell and was having, you know, someone with a disability was having a seizure and fell out of a wheelchair. Stuff like that. Sometimes it’s hard for people, I find, to approach. If you’re not at that comfort level.

A_STAFF_4

Stigma and segregation, rooted in the town’s history of having had a large institution, are still evident.

I think we have stigma because we had [the institution’s name] here for years. So there’s stigma that goes along with someone with a disability. A_STAFF_4

And we’ve even talked about moving to a community that didn’t have as much, you know, where there wasn’t an institution at one time and where there weren’t all these group homes and everything else, just to get [daughter’s name] away from…. Because she tends to, like I say now, most of the friends she hangs around with, are people with disabilities, because that’s kind of who’s left. And because that’s where the community kind of pushes her that way, you know? And they’re familiar to her so she does what’s easy, whereas she’s quite outgoing and cheery and everything. And if we were in a community where there were, you know, just the odd person with a disability, you know, who happened to be born there – not because there was an institution or group homes or whatever – she would probably have more friends without disabilities and – not that there’s anything wrong with having friends with disabilities- but that’s …But you know, right now, she’s almost forced to make friends with people who have disabilities because those other options are so much harder for her. A_FAMILY_MEMBER_2

I always say I don’t believe in integration, because if you don’t segregate people to start with, you don’t need to integrate. So that’s sort of my philosophy. It [this town] has to get integrated because it’s been so segregated, and it’s going to take, probably, a couple of generations. A_FAMILY_MEMBER_2

Young adults with intellectual disabilities report that interactions with teenagers and as a teenager have been negative. Paid staff and community members concur that there is an issue with teenagers being disrespectful towards persons with disabilities but they note that concerned adults do intervene.

I get treated very badly around here.

By whom?
Teenagers who think they’re cool. A_3
When I was young, I was treated like bad and students being picked on by bullies and being picked on by people. And I didn’t like people picking on me, bugging me and calling me names and calling me not nice names.  
*Does that still happen now?*  
No, it doesn’t now. But it used to when I went to school. It happened to me. A_4

*Is it safe for persons with intellectual disabilities to be out at night?* Maybe in the early part of the evening. It depends. Like in the summertime, I would say no. There’s too many young kids on the streets that are really disrespectful.  
A_STAFF_3

I think if someone with an intellectual disability was out late at night, walking down main street, they could be a target for, you know, umm, teasing and harassment. And they would be primarily from the younger population.  
A_STAFF_1

We had an instance with a fellow who was…tormented by some young people. And it was kind of an ongoing thing and it was one of those vicious circle kinds of things because he would get angry and then he would react and then it would just, you know, that would feed on the whole situation. But people in the community would try to intervene. So I would say yes. I think there’s a sense of (looking after people with intellectual disabilities)...Especially for people who are, who are vulnerable. A_COMMUNITY MEMBER_2

The quiet surrounding offered by the locality is appreciated by young adults with intellectual disabilities but some find the town lacking while others are quite satisfied, especially as they have access to a nearby city for additional amenities.

*What do you do in [name of town]?*  
Not much. Walk around.  
*What’s the best part about living here?* It’s nice and quiet. A_7

It’s fun living in [name of town]. Because there’s lots of stuff to do in [town] and [nearby city]. Like there’s lots of movies and places to buy movies….And I love to shop in [town] and [nearby city]. A_4

*Would you say that people generally enjoy living here?*  
Yes  
*Do you?*
Umm. Yes, but I wish that, I wish there was more, more stuff here. You know, leisurely and in work, for work. …I really, I want to go places. You know, like I did last night (went to the city to watch a sporting event). I want to hang out with my friends….until last year, I didn’t travel a lot. Then last year I finally started travelling, and I haven’t looked back since. And this place, and this [agency] was a big help. We went to a (sporting event) last year. It was my first (sporting event)’s trip I’ve ever gone on, because my family hates, is not a big, are not a big sports fan. A_6

Close relationships tend to be with family members, paid staff, landlords and occasionally neighbours. Some report online friendships.

_Re: close friends_
She considers the teachers, the people that work [at the agency], as much her friends…. [The agency] has been with [name of daughter] since she was two and a half years old so …They’re as much family…(daughter adds) ’Best friend’. A_WITH FAMILY MEMBER_1

_Re: Whom individuals with intellectual disabilities turn to for advice or to share good news_
Probably their friends and their case manager. It’s sad sometimes because that might be the only friend they’ve got, you know, to them we’re their friend. We know we’re not, and we have to keep telling them that. Sometimes we’re all they’ve got. A_STAFF_3

_How often do you spend time with friends?_
I go to [city] once a month and go visit [former landlord] once a month in [city]. But I don’t stay overnight. I just go to see her for supper and stuff and come back home. Because she don’t have any roommate now…. I see [staff] at work every day. And I usually go to her house sometimes to have supper. A_4

Paid staff and community members speak highly of older adults (all men) with intellectual disabilities who are/were (now deceased) recognized by the community for their special character often associated with doing favours (menial tasks) without being asked.

(Speaking of David, a former resident of the institution now deceased): And here he was, you know, years and years later, lived totally by himself. Kept his house absolutely spotless, clean. Hard working guy. And, uh, just a really, really nice guy. And always a smile on his face. He would always be there willing to help out… I knew him for the first four years I was here. And I was just scratching the surface with the guy. And he was, a lot of people, he was well known. When he
passed away, he was on the front page of the paper and everybody. And I think even the headline said, you know, ‘[town] lost one of its greatest citizens’, you know? 

A_COMMUNITY MEMBER_3

Every Saturday, [Bobby] would help him (young man who owns the video store) with garbage and then he and [Bobby] would go out for breakfast together. 

A_COMMUNITY MEMBER_2

One particular guy that I know that sort of independently that does (do favours for others), uh, lives by himself and he uh you’ll see him going through town. His name is [Owen]….If you did try to speak to him he won’t say a whole lot because he sort of just keeps to himself. But he will literally shovel the entire length of the sidewalks from one end of Main Street all the way to the other end. And he’s constantly going around picking up garbage, small pieces, big pieces, and going through and going through all that. He does it on a regular basis. There’s another guy named [Doug]. And he certainly is a little more vocal and always has a big wave for you …he collects bottles and recyclables and he goes through the garbage cans looking for recyclables. But he also goes through the parks where if the kids throw pop bottles in the park here, he’s there cleaning up and cleaning up the park. [Doug], I mean you know, he’s helping keep the park clean so I guess he’s doing all of us a favour. He’s doing the community a favour. And [Owen], when he’s cleaning up and taking care of the sidewalks, he’s doing it for the businesses. And nobody pays him to do any of that. 

A_COMMUNITY MEMBER_3

Work is very important for some young adults with intellectual disabilities and less so to others.

My complaint is that there’s just not enough of the work that I need. You know, like, the, you know, the office kind, you know, accounting. That’s, that’s the kind of stuff I need. I need. You know, to further my skills… 

A_6

Would you like to have a job? 
Some day; I’m not sure doing what. 

A_7

Some caregivers recognize that employment could/should offer more than doing work.

Re: making friends

Having jobs; I mean, a lot of my friends, I’ve met through jobs too, even if I still don’t have that job. So, you know, I hope she keeps her job at the [store]. She loves it. And same with the [in home business]. You know, there might be a customer that she really clicks with and makes friends, so …I mean, this is why I
really encourage her to do a variety of different things, not just, you know, one full-time job. A_FAMILY MEMBER_2

However, opportunities for paid employment for adults with intellectual disabilities are limited locally. Frustration is expressed at the lack understanding on the part of local employers.

Re: employment opportunities for adults with ID:
There may be opportunities. See the hard part of being a small town is, let’s say [staff name] works her butt off, gets [Phil]’s a placement at a garage, because he said he’d like to do mechanical sort of stuff. And he pisses off the garage owner. [Phil] will never work in another garage in the [community]. I mean, there’s a handful of them and his name will be mud all the way around. And by association, her [staff] name will be mud as well. So, there are opportunities. You sort of, huh, you know, you cherish the opportunities like a gem and you wait for the right person to come along. And you hand it to them…We call that setting people up for success. Yes, that’s the euphemism we use! And, umm, a lot of people go to [the nearby city]….You should be able to find local solutions for local problems. I don’t see why we don’t. But that’s not my call. A_STAFF_2

There’s not a lot of paid employment in the [town] (for adults with intellectual disabilities). We have, of course, our high times which is the summer. Other than that, we struggle with the winter months. We don’t have a lot of paid employment. We have a lot of community placements. A_STAFF_4

In Town A, young adults with intellectual disabilities' experiences are influenced by the town's history of having been the site of a large institution for persons with intellectual disabilities. Though the young adults interviewed were too young to have known the institution, staff and community members note that stigma remains; perceptions of difference and how to mitigate them are a concern. There appears to be a high reliance on staff and family members for friendship and to mitigate negative encounters with the community (e.g. abusive teenagers or uncomfortable store clerks). As in the other towns, employment opportunities are limited.
Features of the Lifeworlds of Young Adults with Intellectual Disabilities

To elucidate an understanding of the lifeworlds of young adults with intellectual disabilities, the transcript analysis led to the formulation of meanings (see Appendix H) which were then clustered into themes. Fourteen themes emerged:

1. Visibility
2. Similarity/difference/otherness
3. Specificity of individuals
4. Few and different relationships/social interactions
5. The role of family
6. Struggles to be a productive member of the community
7. Conflicting aims and outcomes produced by developmental service agencies
8. Losses associated with leaving school
9. Inability to change, acceptance of the status quo
10. The value of reciprocity
11. The teenage years
12. The role of religious organizations
13. Lack or insufficient transportation services
14. The attraction of the physical surroundings.

The first 6 themes were common to all three towns (see Tables 8 to 13).
Table 8: Theme Cluster ‘Visibility’ and Associated Formulated Meanings across Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town B</th>
<th>Town A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being seen leads to being recognized and accepted.</td>
<td>The invisibility of the disability can lead to insufficient assistance which is felt as discrimination. Being seen, known, accepted and included are enhanced by the visibility of the disability. Tolerated but not seen/lack of engagement.</td>
<td>Perception that seeing is knowing and accepting. Those more dependent are less likely to be seen and are typically seen in groups ‘always with their own’ or with staff. Those who live independently are more likely to be recognized; with recognition comes respect and concern. For some, the disability label limits being known.</td>
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</tbody>
</table>
Table 9: Theme Cluster ‘Similarity/Difference/Otherness’ and Associated Formulated Meanings across Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town B</th>
<th>Town A</th>
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</thead>
<tbody>
<tr>
<td>Community involvement is easier for those that are seen as similar.</td>
<td>In-migration</td>
<td>Independence (less obviously disabled) leads to frequently being seen which combined with conformity leads to acceptance. Those more dependent are less likely to be seen and are typically seen in groups “always with their own” or with staff. Access to the community leads to acceptance which leads to reduced perception of difference. Stigma and segregation, rooted in the town’s history of having had a large institution, is still evident. Community members experience discomfort when interacting with adults with intellectual disabilities.</td>
</tr>
<tr>
<td></td>
<td>Stereotype, prejudice, discrimination Lack of awareness of how to engage with persons with intellectual disabilities.</td>
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</table>
Table 10: Theme Cluster ‘Specificity of Individuals’ and Associated Formulated Meanings across Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town B</th>
<th>Town A</th>
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</thead>
<tbody>
<tr>
<td>Social interactions are stressful for some.</td>
<td>Being seen, known, accepted and included vary. These are enhanced by the family’s prominence in the community, the social skills of the young adult with an intellectual disability and his/her parents, and the visibility of the disability.</td>
<td>Recognition of the uniqueness of each person whether disabled or not in their ability to be accepted and be accepting.</td>
</tr>
</tbody>
</table>
Table 11: Theme Cluster ‘Few and Different Relationships/Social interactions’ and Associated Formulated Meanings across Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town B</th>
<th>Town A</th>
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<tbody>
<tr>
<td>There is ambivalence about living in the town; it offers a peaceful quiet setting but there is a desire for more opportunities and social interaction. There are very few organized social and recreational activities for young adults.</td>
<td>The internet is used to make and maintain long distance relationships. Social activities, even those organized by the agency, are not for everyone. Contrasts with larger centers are both positive (safety) and negative (opportunities for social and educational pursuits).</td>
<td>Staff/landlords are seen as friends/family. Online friendships Neighbors</td>
</tr>
</tbody>
</table>
Table 12: Theme Cluster ‘The Role of family’ and Associated Formulated Meanings across Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town B</th>
<th>Town A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extended family as contributing to sense of belonging in the community.</td>
<td>Being seen, known, accepted and included vary. These are enhanced by the family’s prominence in the community, the social skills of the young adult with an intellectual disability and his/her parents, and the visibility of the disability. Affordable housing is limited but some parents are finding solutions.</td>
<td>The importance of family ties. Being known and being from a family that is respected.</td>
</tr>
</tbody>
</table>
Table 13: Theme Cluster ‘Struggles to be a productive member of the community’ and Associated Formulated Meanings across Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town B</th>
<th>Town A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid employment is possible for some but opportunities are limited.</td>
<td>The social benefits of employment are recognized. There are civic engagement opportunities for young adults with intellectual disabilities but some symbolic participation.</td>
<td>Work is very important for some and less so to others. Limited paid employment for adults with intellectual disabilities locally. Frustration at lack understanding on the part of local employers. Recognition that employment could/should offer more than doing work. Patchwork of activities fill a week.</td>
</tr>
</tbody>
</table>

There is a sense across all three small town and rural communities that young adults with intellectual disabilities are seen and known. Being known is associated with doing things that other members of the community do and generally leads to support and acceptance. However, those with more severe disabilities are less likely to be seen and continue to be perceived as different. The experience of inclusion varies across individuals and tends to be a function of their ability/disability, personality and the role of their family in the community. In all three towns,
young adults with intellectual disabilities experience struggles to be productive members meaningfully engaged in activities on a daily basis.

In addition, three common themes emerged for Towns C and B (see Tables 14 to 16). In these two towns, the conflicting aims and outcomes produced by developmental service agencies were apparent as were the losses experienced by young adults with intellectual disabilities upon leaving school. These two towns are also characterized by an acceptance of the way things are, particularly in relation to the low employment of young adults with intellectual disabilities.

Table 14: Theme Cluster ‘Conflicting aims and outcomes produced by Developmental Service Agencies’ and Associated Formulated Meanings across two Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social segregation occurs. Agencies may play a part in it.</td>
<td>The agency fosters a sense of community for those it supports.</td>
</tr>
<tr>
<td></td>
<td>Many adults with intellectual disabilities are reliant on the agency to provide a patchwork of day activities; others feel unsupported or wishing the agency could do more.</td>
</tr>
<tr>
<td></td>
<td>Agency as hindering social inclusion</td>
</tr>
</tbody>
</table>
Table 15: Theme Cluster ‘Losses associated with leaving school’ and Associated Formulated Meanings across two Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town B</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a loss of contact with friends after high school; there is a sense of being left behind.</td>
<td>Transition from school meant loss of connectedness as well as day activities.</td>
</tr>
</tbody>
</table>

Table 16: Theme Cluster ‘Inability to change, Acceptance of status quo’ and Associated Formulated Meanings across two Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town B</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a desire for paid employment but no concrete planning or preparation for employment.</td>
<td></td>
</tr>
<tr>
<td>There is a perception that if young adults with intellectual disabilities are staying it is by choice.</td>
<td>Paid employment opportunities are scarce for all. Employment is seen as something that comes along rather than something adults should plan for.</td>
</tr>
</tbody>
</table>

Town C and A had three themes in common (see Tables 17 to 19). The attraction of the physical surroundings is apparent to young adults with intellectual disabilities. Many of them do favours for others and receive favours from their fellow community members. Lack of understanding and respect from teenagers towards persons with intellectual disabilities was only noted in these two towns.
Table 17: Theme Cluster ‘The attraction of physical surroundings’ and Associated Formulated Meanings across two Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town A</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is ambivalence about living in the town; it offers a peaceful quiet setting but there is a desire for more opportunities and social interaction.</td>
<td>Quiet is appreciated but some find the town lacking while others are quite satisfied especially as they have access to a nearby city for additional amenities.</td>
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Table 18: Theme Cluster ‘The value of reciprocity’ and Associated Formulated Meanings across two Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town A</th>
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</thead>
<tbody>
<tr>
<td>Some adults with intellectual disabilities enhance others’ sense of community. Reciprocity is natural for many young adults with intellectual disabilities.</td>
<td>Adults with intellectual disabilities receive and do favors from others.</td>
</tr>
</tbody>
</table>

Table 19: Theme Cluster ‘The teenage years’ and Associated Formulated Meanings across two Towns

<table>
<thead>
<tr>
<th>Town C</th>
<th>Town A</th>
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</thead>
<tbody>
<tr>
<td>Youth are not seen as supportive of persons with disabilities.</td>
<td>Interactions with teenagers and as a teenager have been negative. Teenagers are disrespectful but concerned adults intervene.</td>
</tr>
</tbody>
</table>
Towns B and A also had two themes in common (see Tables 20 and 21). In these towns, religious organizations are noted for their engagement with young adults with intellectual disabilities. Lack or insufficient transportation services is acknowledged to have a significant impact on the lives of young adults with intellectual disabilities in these two towns.

Table 20: Theme Cluster ‘The Role of religious organizations’ and Associated Formulated Meanings across two Towns

<table>
<thead>
<tr>
<th>Town B</th>
<th>Town A</th>
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</thead>
<tbody>
<tr>
<td>A perception that the more evangelical groups are very open and welcoming.</td>
<td>A sense that religious organizations should be and are more accepting of persons with disabilities.</td>
</tr>
</tbody>
</table>

Table 21: Theme Cluster ‘Lack or insufficient transportation services’ and Associated Formulated Meanings across two Towns

<table>
<thead>
<tr>
<th>Town B</th>
<th>Town A</th>
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</thead>
<tbody>
<tr>
<td>The cost of getting to work can be a barrier to employment.</td>
<td>Lack of transportation limits all young people who do not drive.</td>
</tr>
<tr>
<td>Transportation – available but not meeting all needs.</td>
<td></td>
</tr>
</tbody>
</table>

Community Silences

The interview data synthesized in this section provide further insight into the experiences of young adults with intellectual disabilities across the three towns. As with the measures of sense of community, belonging and social interaction, the interview data identify commonalities across the towns (themes 1 to 6). The interview data also point to perceptions that are unique to
certain towns. As the thrust of this thesis is to examine how communities contribute to or hinder social inclusion, the distinctive features of each town will be examined in detail. To do so, I focused on the silences in the interview transcripts so as not to be overly influenced by responses which may have been biased by a desire to present one’s community in a positive light. What follows is an examination of what was ‘not said’/not revealed as a theme in each town and the questions their absence raises. The questions will inform the analysis of the impact of the context in subsequent chapters.

Two features of rural or small town living are the positive impact of the landscape on its residents and the reliance on others (reciprocity). While both were expressed by respondents from Town C and Town A in relation to the experiences of young adults with intellectual disabilities, they were absent from the transcripts from respondents of Town B.

- Does Town B have fewer natural attractions or are they less accessible to or less a part of life for young adults with intellectual disabilities?
- Is reciprocity not a distinctive feature of this town or are the roles of young adults with intellectual disabilities living in Town B with regards to reciprocity different than that of other community members?

Two other common features of rural and small town living are the traditional role of religion and the lack of or inadequate public transportation. Both were themes identified from the interview transcripts of participants from Town A and Town B. Town C was the only town where the role of religious organizations was not identified as having a particular relevance to the experiences of young adults with intellectual disabilities. Also, while respondents in Town A
and Town B identified transportation as a barrier to social interaction and community engagement, respondents from this town did not. In addition Town C is the only place where young adults with intellectual disabilities did not report negative experiences with teenagers.

- Is the role of organized religion overall different in this town?
- Have transportation solutions been developed in this town?
- Are teenagers more tolerant/accepting of difference in this town?

Unlike in Town B and Town C, young adults with intellectual disabilities living in Town A do not appear to be affected to the same degree by the formal service systems (education and developmental services). In Town A leaving school does not appear to have resulted in loss of social interactions and activities to the same extent it has in the other towns. Furthermore, the developmental service agency in Town A is not perceived (as in the other two towns) as possibly contributing to segregation of young adults with intellectual disabilities.

- Do more young adults stay in the town upon high school graduation?
- Is the developmental service agency in this town adopting different approaches to inclusion?

Combined with the results from the previous chapter, the analysis of the interview transcripts has confirmed the lack of universality of experience for young adults with intellectual disabilities in rural small town Ontario. Some of the themes common to all three towns such as visibility, similarity/difference/otherness and specificity of individuals are likely not unique to rural experiences. Similarly, other themes such as the role of family, struggles to be a productive member of the community may be unique to small towns but not unique to the experiences of
young adults with intellectual disabilities. The one common theme that may be most pertinent to their experiences regardless of the town they live is that they have few and different relationships/social interactions.

The eight themes that emerged but which did not apply to all three towns provide a lens for the analysis of context in the next chapter.
Chapter 8: Impact of Context

Multiple sources of information are used in this chapter to examine the impact of context on the experience of young adults with intellectual disabilities depicted in the previous chapter. First quantitative results of the AIMS Interview characterize the ways in which young adults with intellectual disabilities are supported in each town. Additional qualitative data from the interviews with all participants are used to further describe each town. Previously reported census and sense of community data are then combined with these two new sources of information in summary tables to complete the profile for each town and contrast the three towns’ contexts relative to the experiences of young adults with intellectual disabilities.

How are Young Adults with Intellectual Disabilities Supported in Each Place?

The AIMS Interview (with caregivers of the adults included in the study) was used to characterize each town in terms of the extent to which the supports provided to the young adults could be said to favour assimilation, integration, marginalization or segregation. Supports are deemed to favour integration when the special needs of the individual are recognized and supported alongside non-disabled individuals. Segregation occurs when the special needs are recognized and supported predominantly in group settings including three or more others with disabilities. Assimilation occurs when an individual is included in the mainstream without special accommodation of their disability-related needs. Finally, marginalization is said to occur when the individual is excluded from participation as a result of his or her disability-related needs not being supported.
Areas of support examined included those leading to engagement in productive activities (education, employment, volunteering), social activities and recreational activities. The results show that the young adults with intellectual disabilities included from the three towns tend to be integrated for recreational activities. Half were segregated for social activities, and almost half were segregated or marginalized in the area of productive activity.

As shown in Figures 8, 9 and 10, a different picture emerged for each town in relation to how the individuals included in the study were supported. While these profiles cannot be said to be representative of the towns (just as the individuals studied may not), they provide a context within which to interpret the reported experiences of the young adults included in the study.

Figure 8: AIMS Profile for Town C

Note: n=6; 17% have developmental age <17 years; 8% require infrequent or no supports; 83% are men
Figure 9: AIMS Profile for Town B

NOTE: n=5; 80% have developmental age <17 years; 40% require infrequent or no supports; 40% are men.

Figure 10: AIMS profile for Town A

Note: n=7; 86% have developmental age <17 years; 29% require infrequent or no supports; 43% are men.
In all three towns, integration was more likely to be the approach favoured by the service system when it came to recreation. This means that young adults with intellectual disabilities were supported to engage in recreation with non-disabled peers. In Towns C and A integration characterized the recreation opportunities available to all the young adults with intellectual disabilities included in the study. In Town B, some young adults’ supports for recreation were characterized as segregated.

Segregation was the predominant approach to meet the young adults’ social needs in Towns A and B while in Town C’, the full range of approaches were apparent. Segregated social supports included dances or clubs for persons with intellectual disabilities only.

Efforts to engage the young adults in productive activities are often lacking as reflected in the proportion for whom this domain is rated as 'marginalized' (excluded from participation as a result of disability-related needs not being supported). This is mostly the case for individuals in Town A while in Town 'B' segregation dominates and in Town 'C' half of the young adults engage in integrated settings for employment or volunteering.

**What is Each Place Like?**

In addition to revealing the experiences of young adults with intellectual disabilities in their respective small town and rural communities, the interviews allowed for an in-depth description of the named places. Citing the various members, each town is described in this section.
**Town C.** The town is described as “very inclusive”. The people are “very friendly and easy to get along with”. The way of life is “much more relaxed than city living”.

It’s just a nice little historic town. And everybody knows everybody else. Sometimes that’s good; sometimes it’s not. Mostly people are very understanding, helpful, good to each other.

Reciprocity is seen as an essential part of small town living: “…that’s part of a small community; you fill in where you’re needed.”

You come to know who your neighbours are, and if they’re not able to plow themselves out, you help them out. I think the experience in the Ice Storm of 1998 showed how strong a community we were in terms of coming together. If there’s a crisis, people will get involved.

And civic participation is a defining feature.

Many people I knew in the urban areas, they went to work, and they were involved in their family, and that was the extent of their life. And I don’t think I’ve met anyone like that in this area. You know, they may work, and they have their family, but they’re also a member of the Lion’s Club, or a member of the Legion, or a member of the church, or something like that. So I think most people – the majority of people- are involved in some way, with some kind of group or organization.

The natural surroundings are seen as exceptional and a way to stimulate the local economy through tourism but there is a love/hate relationship with the resulting summer invasion.

We’re very close to urban areas, yet to me, the environment is very high quality. We have endangered species. We have threatened species. We have excellent water quality….I think environment is really the key thing, the attraction here that I enjoy. The air quality, the water quality, the quality of the earth, sort of thing, the access to the flora and fauna…. We have wonderful resources.

…and after the public sector, the next biggest employer is the tourism industry. But it’s very seasonal. The economy of this area floats really on the tourists. They
aggravate us to no end, but they bring in enough money to keep us alive….
Wouldn’t have the quality of life that we have without the tourists always coming in. C_COMMUNITY MEMBER_2

Having many extended families in the area is seen as facilitating communications: “[t]here are many families that are generations of families in this area. So…the news gets around.”

C_COMMUNITY MEMBER_1 The presence of Aboriginal People in the town is also seen as having a positive influence.

… generally speaking, it’s a very friendly and sharing community. We have to be…the atmosphere, particularly in the school but also in the community and at community gatherings, is very much like a family. And that’s not just a small community thing. I think it’s partly our Native heritage…the Native way is extended family. It’s very much an extended family type of relationship. And that filters into here….And for that reason, I think that there is a lot more tolerance that people who don’t know us tend to give us credit for…I think it (the way minorities are treated)’s better than most places.” C_COMMUNITY MEMBER_2

There is a very strong sense of belonging which emphasizes some differences within the community.

It’s a very tight-knit community. Because it’s rural, a lot of people are related and a lot of people have known each other for a long time….You almost have to be second generation before you’re sort of considered, I think, you know, sometimes before people say ‘Oh yeah, you’re….’ You know, like our house, we’ve been here for almost twenty years and people still call it the old [name of previous owner] house because the [name of previous owner] used to live there so…I mean, a lot of people have had a lot of history here for a long time. C_STAFF_1

And there is a recognition that the town is changing:

That [people thinking of themselves as part of the community] is changing too. I think we are, we are getting a lot of retirees, people who are retiring at their cottages, they’re turning into year-round homes. So, umm, it’s very mixed right now. I think four years ago, it was even very different. Everybody so much more felt local. And then today, it’s more people saying, ‘I’m not really local; I’m from somewhere else.’…So they’re not really part of the culture yet, as far as judging themselves….We’re very much a community in transition with those kinds of demographics. C_COMMUNITY MEMBER_3
Some community members perceive an increasing openness to newcomers and differences.

I think that [thinking of self as part of the local area] happens earlier now than it used to. Like when I first moved here, you weren’t a local until you were second generation….But over the past years, there’s been more change, turn-over in the population… C_COMMUNITY MEMBER_2

The community doesn’t have a dominant group, and so everyone has to say, ‘you know, if you’re here, you’re here.’ Wherever you came from, whatever you have to offer….There’s sort of a general lack of judgment, because the community is not in the position to judge…I think that it works for people with intellectual disabilities….They’re as much a part of the community as anyone else. C_COMMUNITY MEMBER_6

Many who are new or who have returned to the town report being drawn to it.

I have lived here for 15 years,…my family has had a cottage here for 6 generations. So I considered it home. Just moved here…from the Toronto area….It’s a beautiful place to live, and I like to do things outdoorsy. So that’s an emotion for me towards it. C_COMMUNITY MEMBER_7

I’ve always lived in rural communities… This is more rural than what I was accustomed to before, so it was a wonderful change. And it was something that I sought out. I’m not here by default. I researched it and chose to be here, so it was a very intentional decision. C_COMMUNITY MEMBER_3 (in town for 4 years)

It is acknowledged that while some choose to come or return some choose to leave; “I think those who are aching to get out, get out. So those that stay here are happy with staying here.”

C_COMMUNITY MEMBER_7 There are few opportunities for youth.

The youth are less likely to be involved in groups. They often have to go away for their schooling and then go away for work. Even if they live here, they probably have to work elsewhere or not work at all. But I think as people get older, most of them involve themselves in something. C_COMMUNITY MEMBER_7

There’s bingos or there’s card games, but there’s really nothing suitable for the younger generation. C_STAFF_2

If you live in the area, then presumably you like boating, snowmobiling, going on the ATVs, riding horses. You know; the outdoor recreational activities. You might become involved in the theatre. But if you don’t want to do those things,
well, you’re very, you’re very limited. And I think it’s a good area for children when they’re small. It’s a nice area when they’re adults. But it’s a little hard on young people if they’re not into the outdoor sports. C_COMMUNITY MEMBER_1

It is therefore not surprising that when asked what the town most needs, the overwhelming response was a venue of some sort: “a community center” C_COMMUNITY MEMBER_2 “a proper gymnasium, a youth center” C_COMMUNITY MEMBER_6 “Tim Horton’s and McDonald’s, Burger King, Kentucky Fried Chicken.” C_3 “Hang out places. A nice bar for bringing people together.” C_5

Many residents rely on social assistance - “We have a larger than average number that are on some form of social assistance.” C_COMMUNITY MEMBER_7- but the level of poverty is seen by some as an equalizer.

It’s not a wealthy community. Umm, unemployment is still very high. Must be very difficult to raise a family here. We know a number of people who have multiple jobs…. Just to keep paying the bills…and you have to do that in order to … just to make a living….to raise a family. C_COMMUNITY MEMBER_4&5

And it’s very poor, which is an advantage. It’s …there’s no solid middle class. Therefore the pressure to dress the class doesn’t hit too heavily on people….I don’t have a sense that kids need to have a certain amount of money to hang out with certain kids. There’s none of that; because there’s no one with a lot of money. There’s just so few. C_COMMUNITY MEMBER_6

While the town is reported to be a safe place to live, “there’s people who are victims of domestic assaults. Relatively high on domestic assaults, I think.” C_COMMUNITY MEMBER_6 and “... property theft is, unfortunately, a fairly common crime up here. I think it relates to that poverty issue and things like that. Unemployment and things like that.” C_COMMUNITY MEMBER_3

The town is aging and this demographic change is the result of young people moving away for work and retirees moving in for leisure.
…some do [young adults leave after high school], and some come back. But, no, the population is aging. If you look at the demographics, the population is aging, and kids do leave for opportunities. C_COMMUNITY MEMBER_6

We have a large retirement group community, very large. People that have retired from professional jobs in other places and come here just to relax and enjoy themselves. So there’s quite a few seniors’ activities in the area too…glee clubs, travel clubs…Lions’ Club, the Legion, and women’s church groups. So there’s a lot of those types of activities to serve the older citizens. C_COMMUNITY MEMBER_7

The recent increase in retirees coming to live in the town is seen as contributing to the economy but also contributing to the instability.

Early retirees stay from 50 to 70 then resell to move closer to services, another 50 year old moves in brings a lot of energy to the community. C_COMMUNITY MEMBER_6

There is concern for the viability of the town:

It’s quite a diverse, quite a physically scattered community….My sense is that the community is under threat, constantly under threat. That’s just the reality. There just is not enough people. And people are scattered. And the traditional way of life, the rural way of life, has disappeared here very, more quickly than other places because the land is not viable for agriculture….It’s not growing and it’s aging….There’s no real economic driver here except for the summer. …Retail is a disaster. Stores…[are] closing here….There’s no retail in any of these towns… C_COMMUNITY MEMBER_6

The proximity to larger centers is seen as a positive feature.

The ability, to me, to access communities, urban communities….They’re accessible but they’re not in your day to day life. They’re a choice, and you can function and address all of your day to day needs in a small rural community. But if you need those resources, the larger municipality, hospital care, universities, those kinds of things…[urban center] is far enough from [larger centers] that it has its own autonomy. It’s rare that you would have to travel outside of the region for a service. C_COMMUNITY MEMBER_3

With regards to persons with intellectual disabilities, there is a perception of a higher prevalence in the town.
There’s a fair number of people [with intellectual disabilities] relative to the population. C_COMMUNITY MEMBER_6

A distinction is made between those native to the area and those brought in.

Some of them have been born here, and we ended up with a very good service to support them. And then, some others are parachuted in. C_COMMUNITY MEMBER_7

There’s two kinds of intellectually challenged people. There are the ones who were born and grow up here. And there’s a fair amount of that because of poverty in the past and a lot of alcoholism. So there are people like that. But there are also the ones who have come in as part of the services that are provided here. …The one that have been brought in, I think it (social inclusion)’s a little harder for them…. C_COMMUNITY MEMBER_4&5

Finally, the economic impact of the support services for persons with intellectual disabilities is recognized. “Actually, [developmental service agency], I believe is our largest employer.” C_COMMUNITY MEMBER_3

I say if facetiously, but what in many communities is a problem [referring to individuals with intellectual disabilities], here is an employment opportunity. C_COMMUNITY MEMBER_4&5

In summary, Town C is experiencing economic uncertainty relying on tourism and social services as its main sectors of employment/revenue. Its population is aging with younger people moving away and retirees moving to the town. Civic engagement and strong family ties are apparent. There is a perception that there are more persons with intellectual disabilities than expected.

**Town B.** Generosity is a key attribute given to this town by its residents.

If there’s a fire, somebody’s lost all their stuff, there’s always people usually picking up quite fast to, you know, to help them out. B_COMMUNITY MEMBER_4
It’s a wonderful community. Actually I was just reading earlier an article about how generous the community is when it just opened the Hospice House here and when it comes to just about any of those kinds of things here, the Fire Department draws or any of those kinds of things, the hospital, the dialysis, the community is just so generous it is unbelievable; a real neat community that way.

COMMUNITY MEMBER_6

[Name of town] is a very giving community. If anyone of them needed a kidney transplant, the town would do anything to help. Regardless of religion, disability or background. Everybody comes together and it really helps.

COMMUNITY MEMBER_1

As the mother of a young man with an intellectual disability said,

There’s a good spirit in this town….It’s like ‘Roll your sleeves and get it done!’ It’s kind of like that’s the way the attitude is, like, if we don’t have it, we’ll try to do the best we can to fill that need.

FAMILY MEMBER_4

Part of this sense of responsibility for fellow residents stems from close family and friendship ties. “There’s friends and family… We’re well connected.”

FAMILY MEMBER_3

“Oh, the connections here are phenomenal amongst the local families.”

COMMUNITY MEMBER_3 “It’s very homey. The people, once they get to know you, they become loyal friends.”

COMMUNITY MEMBER_2

Neighbours also tend to play a key role in supporting each other.

You wouldn’t survive without your neighbours. Like, I mean, I’ve got one that if I’ve got problems, I can pick up the phone and say ‘[Doris], I need your help! NOW!’

FAMILY MEMBER_4

We have six direct neighbours where we live…so we are always watching for each other’s goods, each other’s kids. You know, the lady across the road helps me out with a couple of things in the year and I’m the one who’s on call when she locks her keys in or out, or last spring I was helping her bail out her basement at one point in time….That (people doing and receiving favours from neighbours)’s very much part of the community spirit here for sure.
My neighbours would do almost anything for me. Like, they let my dog out. They put wood on my fire. They see that we’re gone away for a long time during the day and it’s the middle of winter and they notice we’re not there; they go in and put wood on our fire….Help out as far as vehicles….Pretty much anything. I’m lucky. “Is that pretty much the rule or are you lucky?” I think because I’m in an area – I’m in like a small subdivision – we all know each other really well. I think that has a lot to do with it. But up here, you could be pretty much guaranteed that most people know their neighbours. You know who lives around you.

B_COMMUNITY MEMBER_5

Some note, however, that for some newcomers it is difficult to establish close friendships in part because of the close ties which exist. “If you’re an outsider, not born and raised here, you’re not accepted the same way. It’s a big issue.” B_COMMUNITY MEMBER_4

There’s a lot of people here that, you know, say they’re forty years old and their only friends are the friends they’ve had since grade nine, sort of thing, which is tough for new people to break into those groups, for sure. B_COMMUNITY MEMBER_5

Like they’re friendly when you’re downtown and that; we’ve never had a problem with that. But unless you sort of get connected, it seems like everybody sort of comes in, does their business, and they’re gone if you haven’t got that circle. I’ve always felt, well, perhaps if we were interested in being part of the Legion…going to Bingo, or, you know, sitting down at the local bar; maybe we’d meet a few people. But if that’s not part of your lifestyle, it makes it a lot more difficult. B_WITH FAMILY MEMBER_2

Organized religion is prominent and is reflected in more conservative views. There are “a lot of religious groups in this town.” B_COMMUNITY MEMBER_4 “There is a huge religious factor here.” B_COMMUNITY MEMBER_5

[name of town] has always been quite religious….There’s a very strong evangelical born-again population here. B_COMMUNITY MEMBER_3

…a redneck sort of way of thinking, here…I don’t know how to explain that one. I say that, I mean kind of; they have certain beliefs and values. This is a very, um, a very, there’s a very, a large amount of very religious people here…A lot of it, I think comes back to the very hardcore, the religious backgrounds here. B_COMMUNITY MEMBER_5
When asked what the town is most in need of, many found it difficult to identify a specific service, a few mentioned a pool or a skateboard park; two things that the community is already trying to address. Two young women with intellectual disabilities commented on the need for affordable shopping; noting “It’s priced for tourists, you know.” B_WITH FAMILY MEMBER_2

While some characterize the town as “a very self-sufficient community…People are independent. There is a northern flavor. You have to prove yourself.” B_COMMUNITY MEMBER_3 It is also described as “a little egocentric”.

[Name of town] is; when we think of ourselves. We’re part of [name of county] County. But we think of ourselves as a different part of [name of county] County. And that’s been sort of a pervasive philosophy, I think, up here – we’re a little different, we’re better. But we’re different. We hate to get lumped in with [nearest city]. “Why do you think that is?” It helps maintain our identity. I think the main reason is probably, it’s more geographic isolation, than anything else. I mean, we’re 100 kilometers from [nearest city]. It’s a totally different environment, different weather. B_COMMUNITY MEMBER_7

Because of its geographic location, the town is “a commercial hub with a market draw of 30,000 to 40,000. We have banking, insurance. It’s a service hub: federal, provincial, county services are here.” B_COMMUNITY MEMBER_3 The local economy relies on the service sector. “There’s a lot of employment for young people. But it tends to be skilled employment.” B_COMMUNITY MEMBER_3

We don’t have a lot of manufacturing or industrial employers, and it’s a shame. I wish we did. I wish we had people who were able to provide a better level of income to our residents. That’s where we are very vulnerable. B_COMMUNITY MEMBER_3

As a result of the type of employment opportunities available, “we lose a certain percentage of the population, young population, to the outside.” B_COMMUNITY MEMBER_6 However,
“a lot of people, if they go away to school or for work, return.” B_COMMUNITY MEMBER_1

“Often, they’ll go out to get their education and their training. And then they’ll come back because they like the social aspect of [name of town].” B_COMMUNITY MEMBER_2

“...Kids like to raise their kids here if they moved to the city of whatever.” B_COMMUNITY MEMBER_4

I was born here. My grandmother lived here. I used to come and spend my summers with my Grandma. And I absolutely loved my Grandma, and I always loved my summers here…this was a place where I had lots of happy memories. B_FAMILY MEMBER_4

They’re happy to be back. That was always their goal: was, you move away, but when you’re ready to retire, you come home! And, so many people do that, so many of our people. They leave, but they want to spend their last years here. B_COMMUNITY MEMBER_3

Others are also attracted to the area which has led to growth and change. “We are definitely seeing growth here. Huge growth. The two grocery stores, the relatively new Canadian Tire store, there is talk of Walmart.” B_COMMUNITY MEMBER_6

“We are an aging community.” B_COMMUNITY MEMBER_3

[I]t’s been a whole transition of people coming in, a whole migration of people moving out of the city in those twenty-some odd years....Different industries and retails and things like that have really made the area bloom. But it still has an old town feel....Much more diversified....And religious groups that have flourished in different ways. B_WITH FAMILY MEMBER_3

It’s changed quite a bit in the last few years...I don’t know if they’re positive, but it’s development. It’s a simple thing, but we’ve gone from two sets of lights to four sets of lights. And that’s a big change. We’re down to box stores. A lot of retired people moving in to the community, so our population base is increasing. B_COMMUNITY MEMBER_7

A main attraction of the area is its natural surroundings.
I think it’s so beautiful. It’s just a beautiful, beautiful town. The rocks, and the lakes…just do something to me. Like, I find it a very peaceful place. It’s like because it’s so rugged, man hasn’t been able to carve (his) name in it too much because of the, like the rock just says, it’s still the way God made it. B_FAMILY MEMBER_3

It’s basically an all-season playground….So if you enjoy water activities, summer activities, there’s lots to do. There’s a lot of lakes. If you enjoy snowmobiling, there’s lots of snow here usually in winter…it just provides a lot of outdoor activity. B_COMMUNITY MEMBER_5

Much of the town’s recreation centers around the outdoors which also attracts many tourists.

“It’s absolutely wonderful here. … of course all the outdoor activities we just went through. The hunting season is over now; in the fall it brings tremendous dollars in to the area.”

B_COMMUNITY MEMBER_6

You just missed the biggest recreation event of the year…hunting season….That’s again where a lot of the motels and hotels get their business from. It’s huge….A lot of money is spent during hunting season.

B_COMMUNITY MEMBER_7

During the summer, we have like four times our community. It doesn’t double, it doesn’t triple, it probably goes to at least four times bigger. Like, it’s just unreal how big….You know, like all the cottagers, and all the tourists. It’s really a tourist town. B_FAMILY MEMBER_3

Hockey is huge here….There’s a volleyball league here; there’s a badminton league here; there’s a lot of sporting. There’s baseball in the summer. So as far as recreational stuff, a lot of it is offered right here. Like the only thing that people find they have to go out of town for is maybe some swimming. We don’t have a community pool here. That seems to be THE one thing that you have to go elsewhere for. B_COMMUNITY MEMBER_5

Some recognized further untapped potential in the physical surroundings.

Recreationally, I would love to see more instruction things, for example: we have bow-hunting in this area, but no one’s teaching archery ….We have miles of lakes and rivers. We have no canoeing instruction. We have hills like you wouldn’t believe, but nobody is teaching repelling. B_COMMUNITY MEMBER_3
While residents speak very highly of their town, they recognize that it is “not perfect”; particularly in terms of eliminating violence against women.

There’s a lot of domestic assaults, assaults, threatening, theft, break-and-enters.

**B COMMUNITY MEMBER_5**

I mean we have a women’s program, so obviously abuse is a big issue. Umm. It actually is a very large issue; spousal abuse, and to some degree sexual abuse.

**B COMMUNITY MEMBER_3**

In summary, Town B is remotely situated and is a service hub to other smaller communities. Organized religion is prominent and values tend to be more conservative. Close family and friendship ties are apparent but make it difficult for newcomers to feel welcome. There is a perception that there are more persons with intellectual disabilities than expected.

**Town A.** This place affects its residents and visitors’ senses in distinct ways in contrast to Towns B and C:

When we were visiting, we drove in [the town], thought it was really nice, and ended up buying a place here….It smelled different…you can smell strawberries and apple blossoms, and honestly, it was just totally different from anywhere else we had ever lived. **A FAMILY MEMBER_2**

Of course, the physical surroundings; it’s very beautiful. There isn’t anywhere you go where it isn’t just, you know, there aren’t just astounding things to see. **A COMMUNITY MEMBER_2**

It is also felt beyond the sights and smells; “It’s a friendly place, it’s warm. It’s kind of like getting wrapped up in a blanket.” **A FAMILY MEMBER_1** “Felt very loved and accepted by the community.” **A COMMUNITY MEMBER_4**
A lot of recreation revolves around the water; “boating, anything water-related.”

A_STAFF_3  Not surprisingly, many tourists are drawn to the area.

I would say what makes [the town] special is the tourism…from May to October, [the town] becomes, contains, probably, you know, a small city population…the little shops,…the camping…the historical sites. A_STAFF_1

While tourism plays an important role, the area’s economic base is diverse.

The major employer in [town] would be different levels of government combined…And then agriculture of course. Agriculture sector is the largest industry in [town]…And then the tourism would probably be the third. A_COMMUNITY MEMBER_5

The town is described as “a real go get ‘em community. People have visions and then pull committees together or groups together. I find it pretty dynamic that way.”

A_COMMUNITY MEMBER_4

The community’s very good at working together. That’s one of the real strengths of this community, is that they work very hard to fill gaps…I have never in my experience seen a community that works as well at filling gaps. A_COMMUNITY MEMBER_2

“There is a lot of community pride. … Most of what happens in [the town] is volunteer-driven, and I think that’s because we don’t have the tax base, industrial base to pull on that other urban types of centers have. A_COMMUNITY MEMBER_5

In addition to volunteerism, neighbourliness and reciprocity are also defining factors.

It’s very old-fashioned that way; neighbours help neighbours. A_COMMUNITY MEMBER_4

Because it’s rural and it’s cultural, it travels very quickly that someone needs help, whether it’s the basement flooded, a tree fell on their house, or something happened, you know, and generally very quickly, the word spreads and then the neighbours are there sort of in full force to help. A_COMMUNITY MEMBER_3

It is described as “a very close-knit community” where “everybody knows everybody”.

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It’s more of a community than larger centers….I think that’s part of what makes [the town] special, that you get to know and recognize people….We know our neighbours. They know us. They know our dog.” A_STAFF_2

When you walk along and people know you from somewhere and so they all say ‘hi’ to you. And so there’s that level of what you see in a small town – people knowing other people and saying ‘hi’. A_COMMUNITY MEMBER_1

People, neighbours here still sort of still drop in and talk and visit and stuff like that. A_COMMUNITY MEMBER_3

Despite this closeness, the influx of newcomers causes tensions. “It’s kind of a neat community, but it is changing.” A_COMMUNITY MEMBER_1

With [the town] being marketed the way it is, it’s drawing a different class of people to the area with a different set of values. So there is a bit of a power struggle between newcomers and not newcomers –whatever you want to refer to them as. A_COMMUNITY MEMBER_5

People come here semi-retired, and they came here because they like the way it is and they want to try and make it better from their point of view, from where they stand. And that creates a little bit of alienation because people who are already here don’t always agree with what the….There’s two different visions about what the [area] is and was, type of thing. A_COMMUNITY MEMBER_5

You have a lot of people that come here from Toronto, big cities, and have either bought homes or cottages, summer homes and stuff like that. So, I find the Main Street of [town] is changing a bit to suit those people who have the higher income and stuff like that. A_STAFF_4

Another interesting development is the, uh, the big, big houses being built along the lakeshore. Umm, you know, a very rich population; and that has really impacted on housing values and made life very difficult for some of the seniors who have owned their property for a long time and now there’s huge assessment increases and tax increases. A_COMMUNITY MEMBER_2

Regarding reciprocity, one resident noted “It happens all the time; but not as much as it used to.” and went on to explain

I was talking to [Patricia]….She said it used to be, umm, when a baby was born, you know everybody, the whole community would get together and bring over casseroles or if a place burnt down, people would be there to pitch in and
fundraisers for this and that and the other thing. She said it’s not like that anymore. A_STAFF_2

There is also a decreased sense of safety; “it’s not like it used to be years ago. I find that, like, at night time, you don’t walk outside.” A_STAFF_4

You’ve got that large influx of people from away who are not connected to the community. And when you lose connection to the community and, they’re more anonymous, you have a higher crime rate. A_COMMUNITY MEMBER_1

One resident commented “You don’t have that same rural feel that you used to. I think it’s gotten too popular.” A_FAMILY MEMBER_2

There is also recognition that “the population base here is aging.” A_COMMUNITY MEMBER_3

It’s changed dramatically over the last maybe ten years as we’ve had an influx of seniors, of people coming to [the town], buying houses to retire in, and that has really changed the face of [the town]. A_COMMUNITY MEMBER_2

But seniors are not the only ones attracted to this town.

Right now – and this has happened since I’ve been here – has been the influx of artists, mainly from Toronto. A lot of film-makers here, a lot of writers, painters, sculptors…very vibrant here. It reminds me, although I wasn’t there, of everything that I read about Paris in the 1920s….It’s that level of saturation of people in the arts. A_COMMUNITY MEMBER_4

…what’s interesting in the community right now is that you have a fairly rapid transition in the demographics over the last short period of time – the short period being maybe like the last five or ten years….Prior to that, the vast majority – probably three quarters of the population - was multigenerational. And now it’s probably fifty-fifty or there might even be more people that we could call newcomers….There’s good and bad to all of it. It’s not all negative, it’s not all positive.” A_COMMUNITY MEMBER_5

The above changes appear to have resulted in insufficient attention to the needs of youth. There is a growing recognition of the importance of addressing these.
I think we’re lacking in our facilities for the youth….Thirty years ago, there were two pool halls, a bowling alley, the theatre….There were restaurants where the kids could go and sit at a table for three or four hours or two hours anyways and just have fries and gravy or something like that; it wasn’t a problem. But now it’s been a more high-end type of thing. There’s not a lot affordable restaurants. The pool halls are gone, the bowling alleys are gone, the arcades are gone….There’s really not a lot there that says, you know, ‘welcome’. A_COMMUNITY MEMBER_5

Regarding the need for youth-related facilities, one resident commented “It’s a disgrace where we’re at. We’ve just overlooked it for too long.” A_COMMUNITY MEMBER_5  Another added “It’s taken forever to get these kids a skateboard park. And it’s been the kids really behind it making it happen.” A_COMMUNITY MEMBER_4 Yet another noted “I still think there’s a need for more places, things for young people to do that, that don’t involve organized sports…if you’re not involved in sports, it leaves some holes in your life.” A_COMMUNITY MEMBER_2

It’s an issue for our youth – feeling part of the community, feeling welcomed in the community, and feeling that they have ownership. I think that those are all….Those are very high priorities that we have to address in a proactive way. A_COMMUNITY MEMBER_5

Just look in the paper, there’s always something going on. But it tends to be old retired people or young people with kids. A_STAFF_2

An important geographic feature of this rural community is that it is spread between two major hamlets with the town somewhat centrally located. And there is no public transportation service linking these locations. “There’s a complaint about it (services) being overly centralized.” A_COMMUNITY MEMBER_1

Not surprisingly that when asked what the area needed the most, residents identified either youth-related facilities or public transit.

Definitely transportation. Transportation is such a big thing. And like, I guess, community facilities….I just think that there needs to be more things for young
people. Facilities...Specifically, what I think is needed, I don’t really know. I just know that young people from, you know, 14 to, you know, 28, just need more opportunities to do things. And, umm, a lot of reasons, if there are things going on, a lot of reasons they’re not able to access them is because they don’t have the transportation, you know, so that’s a big one. Transportation is huge.

A_STAFF_1

In summary, Town A benefits from a diverse economic base and a spirit of volunteerism. As a community, it covers a wide geographic area but has no public transportation system. In recent years, it has seen the influx of more wealthy newcomers which has had economic impacts and led to changes to the sense of cohesion among community members. In particular, the needs of youth appear to have been overlooked.

There is a perception that there are more persons with intellectual disabilities than expected.

Once again, these interview data reveal similarities across the small towns studied as well as unique features. In each town, there is a perception of a higher prevalence of intellectual disabilities. However, the reason given for the higher numbers of individuals with intellectual disabilities in the respective towns range from the historical presence of an institution (Town A) to in-migration/service provider creating supports to accommodate individuals from other towns (Town B), and in-breeding, poverty and /or alcoholism as causes of intellectual disabilities (Town C).

Similarly, while all towns are known to attract tourists, the view of tourists/tourism differs significantly across towns. In Town C, tourists are described as an ‘invasion’ while in Town B they are valued for ‘the tremendous dollars’ they bring in.
In each town, members commented on change. In Town A, residents do not feel as safe as they once did. In Town B a shift to more conservative values is associated with the establishment of more evangelical churches. In Town C there is a reported sense of increased openness to newcomers and difference. All changes relate to changes in demographic; the influx of newcomers. Town A is seeing more young artists choosing to live there; it is becoming less inter-generational. Town B is experiencing growth in the service sector which results in working age professional and technicians moving to the area (often individuals who left the town to pursue their education and are returning to be close to family now that employment opportunities are available). In Town C the newcomers tend to be young retirees with time, energy and interest to engage in volunteering.

Summing up, Town A is described as dynamic/responsive to needs, Town B as generous/self-sufficient, and Town C as inclusive. As is increasingly being recognized in research on small towns and rural places in Canada, these descriptions point to the heterogeneity and complexity of small towns and rural places in contrast to earlier research which tended to paint a more homogeneous picture of small towns and rural places in Canada.

**Comparison of the Three Towns with Regards to Context and Social Inclusion**

Table 22, 23 and 24 summarize key findings for each town relative to the other two thereby allowing the uniqueness of each town to be revealed while linking the experiences of young adults with intellectual disabilities to features of their respective towns. Each town contributes to the overall understanding of community among young adults with intellectual disabilities in small town Ontario as outlined below.
Table 22: Findings from Town A relative to the Other Two Towns

<table>
<thead>
<tr>
<th>Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with Community Belonging</td>
<td>Highest</td>
</tr>
<tr>
<td>Adequacy of Social Integration</td>
<td>---</td>
</tr>
<tr>
<td>Sense of Community</td>
<td>lowest</td>
</tr>
<tr>
<td>Lowest Sense of Community item</td>
<td>Perceive selves as dissimilar to others</td>
</tr>
<tr>
<td>Importance of similarity/conformity</td>
<td>yes</td>
</tr>
<tr>
<td>Internet used to support social connections</td>
<td>yes</td>
</tr>
<tr>
<td>Importance of families /prominence in the community</td>
<td>yes</td>
</tr>
<tr>
<td>Loss of contact and support with transition from school</td>
<td>---</td>
</tr>
<tr>
<td>Limited opportunity for productivity roles</td>
<td>yes</td>
</tr>
<tr>
<td>Lack of transportation as a barrier</td>
<td>yes</td>
</tr>
<tr>
<td>Census: Population density</td>
<td>highest</td>
</tr>
<tr>
<td>Census: Population growth/decline</td>
<td>growth</td>
</tr>
<tr>
<td>Census: Proximity to Urban Center</td>
<td>---</td>
</tr>
<tr>
<td>Census: Income Level</td>
<td>highest</td>
</tr>
<tr>
<td>Census: Home Value</td>
<td>highest</td>
</tr>
<tr>
<td>Census: Level of Education</td>
<td>---</td>
</tr>
<tr>
<td>Census: Size of Visible Minority</td>
<td>---</td>
</tr>
<tr>
<td>Census: Size of Aboriginal Population</td>
<td>highest</td>
</tr>
<tr>
<td>Approach to Recreation for Young Adults with ID</td>
<td>Integration</td>
</tr>
<tr>
<td>Approach to Social Activities for Young Adults with ID</td>
<td>Segregation</td>
</tr>
<tr>
<td>Approach to Productive Activities for Young Adults with ID</td>
<td>Segregation/ Integration</td>
</tr>
<tr>
<td>History of institution in town</td>
<td>Yes</td>
</tr>
<tr>
<td>Concern for viability/stability of the town</td>
<td>---</td>
</tr>
<tr>
<td>Developmental service agency seen as hindering inclusion</td>
<td>---</td>
</tr>
<tr>
<td>Prominence of extended family/family ties</td>
<td>lowest</td>
</tr>
<tr>
<td>Prominence of religion</td>
<td>---</td>
</tr>
</tbody>
</table>
Table 23: Findings from Town B relative to the Other Two Towns

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with Community Belonging</td>
<td>---</td>
</tr>
<tr>
<td>Adequacy of Social Integration</td>
<td>highest</td>
</tr>
<tr>
<td>Sense of Community</td>
<td>highest</td>
</tr>
<tr>
<td>Lowest Sense of Community item</td>
<td>Friends not part of everyday life</td>
</tr>
<tr>
<td>Importance of similarity/conformity</td>
<td>---</td>
</tr>
<tr>
<td>Internet used to support social connections</td>
<td>yes</td>
</tr>
<tr>
<td>Importance of families /prominence in the community</td>
<td>yes</td>
</tr>
<tr>
<td>Loss of contact and support with transition from school</td>
<td>yes</td>
</tr>
<tr>
<td>Limited opportunity for productivity roles</td>
<td>yes</td>
</tr>
<tr>
<td>Lack of transportation as a barrier</td>
<td>yes</td>
</tr>
<tr>
<td>Census: Population density</td>
<td>---</td>
</tr>
<tr>
<td>Census: Population growth/decline</td>
<td>decline</td>
</tr>
<tr>
<td>Census: Proximity to Urban Center</td>
<td>farthest</td>
</tr>
<tr>
<td>Census: Income Level</td>
<td>---</td>
</tr>
<tr>
<td>Census: Home Value</td>
<td>---</td>
</tr>
<tr>
<td>Census: Level of Education</td>
<td>lowest</td>
</tr>
<tr>
<td>Census: Size of Visible Minority</td>
<td>lowest</td>
</tr>
<tr>
<td>Census: Size of Aboriginal Population</td>
<td>---</td>
</tr>
<tr>
<td>Approach to Recreation for Young Adults with ID</td>
<td>Segregation/Integration</td>
</tr>
<tr>
<td>Approach to Social Activities for Young Adults with ID</td>
<td>Segregation/Integration</td>
</tr>
<tr>
<td>Approach to Productive Activities for Young Adults with ID</td>
<td>Segregation</td>
</tr>
<tr>
<td>History of institution in town</td>
<td>---</td>
</tr>
<tr>
<td>Concern for viability/stability of the town</td>
<td>---</td>
</tr>
<tr>
<td>Developmental service agency seen as hindering inclusion</td>
<td>yes</td>
</tr>
<tr>
<td>Prominence of extended family/family ties</td>
<td></td>
</tr>
<tr>
<td>Prominence of religion</td>
<td>highest</td>
</tr>
</tbody>
</table>
Table 24: Findings for Town C relative to the Other Two Towns

<table>
<thead>
<tr>
<th>Category</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with Community Belonging</td>
<td>---</td>
</tr>
<tr>
<td>Adequacy of Social Integration</td>
<td>lowest</td>
</tr>
<tr>
<td>Sense of Community</td>
<td>---</td>
</tr>
<tr>
<td>Lowest Sense of Community item</td>
<td>Police not friendly</td>
</tr>
<tr>
<td>Importance of similarity/conformity</td>
<td>yes</td>
</tr>
<tr>
<td>Internet used to support social connections</td>
<td>---</td>
</tr>
<tr>
<td>Importance of families/prominence in the community</td>
<td>---</td>
</tr>
<tr>
<td>Loss of contact and support with transition from school</td>
<td>yes</td>
</tr>
<tr>
<td>Limited opportunity for productivity roles</td>
<td>yes</td>
</tr>
<tr>
<td>Lack of transportation as a barrier</td>
<td>---</td>
</tr>
<tr>
<td>Census: Population density</td>
<td>lowest</td>
</tr>
<tr>
<td>Census: Population growth/decline</td>
<td>growth</td>
</tr>
<tr>
<td>Census: Proximity to Urban Center</td>
<td>closest</td>
</tr>
<tr>
<td>Census: Income Level</td>
<td>---</td>
</tr>
<tr>
<td>Census: Home Value</td>
<td>lowest</td>
</tr>
<tr>
<td>Census: Level of Education</td>
<td>---</td>
</tr>
<tr>
<td>Census: Size of Visible Minority</td>
<td>---</td>
</tr>
<tr>
<td>Census: Size of Aboriginal Population</td>
<td>---</td>
</tr>
<tr>
<td>Approach to Recreation for Young Adults with ID</td>
<td>Integration</td>
</tr>
<tr>
<td>Approach to Social Activities for Young Adults with ID</td>
<td>No predominance</td>
</tr>
<tr>
<td>Approach to Productive Activities for Young Adults with ID</td>
<td>Integration/Marginalization</td>
</tr>
<tr>
<td>History of institution in town</td>
<td>---</td>
</tr>
<tr>
<td>Concern for viability/stability of the town</td>
<td>yes</td>
</tr>
<tr>
<td>Developmental service agency seen as hindering inclusion</td>
<td>yes</td>
</tr>
<tr>
<td>Prominence of extended family/family ties</td>
<td>highest</td>
</tr>
<tr>
<td>Prominence of religion</td>
<td>lowest</td>
</tr>
</tbody>
</table>

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- The highest satisfaction with community belonging in Town A is surprising given it has the lowest sense of community (mainly due to not perceiving themselves as similar to other community members) and greater segregation in social and productive activities (see Table 22). The lower sense of community could be explained by the increased diversity (re: Aboriginal Population), population growth, and high income leading to greater perception of difference. The higher satisfaction with community belonging in this context suggests that community belonging need not always refer to the broader community. Some young adults with intellectual disabilities may experience community belonging because of their close ties and frequent contacts with others who live with similar disabilities.

- Sense of community and adequacy of social integration are highest in Town ‘B’ where importance of similarity/conformity for inclusion is not apparent (see Table 23). More remote settings with declining population and characterized by lower education and less diversity may be characterized by increased segregation; possibly because there are few young adults without intellectual disabilities with whom to associate. Such segregation still confers social integration and sense of community. If people are supported they can feel socially included and part of their community even if the approach to support tends to be in groups with other people with intellectual disabilities.

- The lack of a clear pattern linking characteristics of the town to sense of community/belonging/social interaction or approaches to supports in Town C (see Table 24) suggests that low population density and proximity to an urban center may be important factors related to supports offered to some young adults with intellectual
disabilities as well as their sense of community and satisfaction with community belonging.

The questions raised in the previous chapter are partially answered by the above analysis of context.

- Does Town B have fewer natural attractions or are they less accessible to or less a part of life for young adults with intellectual disabilities?
  - The natural surroundings of Town B are a main attraction of the area and much of the town's recreation centers around the outdoors. It may however be an untapped resource for many young adults with intellectual disabilities who may require assistance and accommodation to enjoy their surroundings due to physical limitations. Young adults with intellectual disabilities were more apt to describe shopping and being a spectator at hockey games as their activities of choice whereas it appears other residents engage in outdoor activities (such as water activities, snowmobiling, hunting). Facilitating common use of spaces and shared experiences does not appear to have been considered as a way of supporting social inclusion.

- Is reciprocity not a distinctive feature of Town B or are the roles of young adults with intellectual disabilities living in this town with regards to reciprocity different than that of other community members?
  - The analysis suggests that the developmental service agency in this town limits opportunities for the development of reciprocity between young adults with intellectual disabilities and community members. The bonds it fosters among
service recipients and with agency staff may insulate young adults with intellectual disabilities from engaging fully with other community members.

- Is the role of organized religion overall different in town C?
  - Indeed, interviews with a variety of community members revealed that religion does not play a dominant role in this town and that church (mainly Catholic and Anglican) attendance is low. The impact of this reduced prominence of religion does not appear to be of relevance to the experience of social inclusion in this town.

- Have transportation solutions been developed in town C?
  - The interview data reveal that town C has a long history of organizing volunteers to solve local problems. They have established a local voluntary transportation system mainly in response to the increasing elderly population. All appear to benefit from reciprocating different 'services' including transportation.

- Are teenagers more tolerant/accepting of difference in town C?
  - Two factors are identified in this town as contributing to tolerance and acceptance of difference: poverty and the presence of Aboriginal People. Poverty is seen as equalizing while the aboriginal culture is seen as unifying.

- Do more young adults stay in town A upon high school graduation (as an explanation for the difference in the associated loss in friendships seen in other communities)?
  - There is no evidence from the examination of census data or the analysis of interview transcripts that more young adults stay in town A upon high school
graduation. However, the young adults with intellectual disabilities in this town were more likely to identify family members and paid caregivers as their friends.

- Is the developmental service agency in town A adopting different approaches to inclusion (as an explanation for it not being identified as contributing to segregation)?
  
  - Based on the AIMS data for the participants from town A, the developmental service agency in this town has a greater tendency to provide segregated social activities than the agencies in the other towns. This however is not perceived by the community as detrimental to social inclusion.

Experiences and resulting sense of belonging are highly variable across individuals and towns resulting from an interplay between spaces/structures, practices, and meanings of the community combined with individual and family characteristics. As shown, examining the interplay rather than individual elements in isolation provides a richer understanding of what it takes for young adults with intellectual disabilities to be socially included.
Chapter 9: Discussion and Conclusions

This thesis posed three inter-related questions: (1) What is it like to be a young adult with an intellectual disability living in a small town in Ontario at the start of the 21st century? (2) How do their perspectives on sense of community differ from that of their caregivers and other community members? and (3) "What is the impact of context on sense of community among the young adults with intellectual disabilities? In this chapter, each question will first be addressed separately by noting the most important findings related to each. As the findings are inter-related they will be discussed in combination with respect to previous research, and their relevance to theory and/or public policy. The chapter concludes with a review of the strengths and limitations of the study.

What Is It Like To Be a Young Adult with an Intellectual Disability Living in a Small Town in Ontario at the Start of the 21st Century?

The young adults with intellectual disabilities interviewed share a common desire to be able to go to places in their towns. Depending on where one lives in relation to the location of desired community spaces, lack or inadequate transportation can be a barrier. It is acknowledged that in some towns, recent changes have resulted in fewer spaces for social interaction of interest to young people (e.g., closure of bowling alley, theatre, and inexpensive restaurants, revitalization of main street) and that new spaces/structures are needed (e.g., fast food venues, sports facility). While young adults with intellectual disabilities recognize and value the peace and beauty of their natural surroundings, few take advantage of the opportunities it offers (e.g., outdoors sports and other recreational activities). This is due in part to a need for supports.
including transportation, funds to purchase equipment and assistance with joining teams or others in organized activities.

The local developmental service agency is a space for young adults with intellectual disabilities to interact with others of all ages who have similar disabilities and the staff who support them. In one town, the agency’s placement downtown is seen as contributing to increased visibility, understanding and interaction with other residents of the town.

Almost all young adults with intellectual disabilities want to contribute to their communities by working but most are unemployed and the few who work do so on a very casual basis mainly at the local developmental service agency. Yet, very few feel the need for post-secondary education in order to be better prepared to contribute to their community. Preparation for employment of young adults with intellectual disabilities does not appear to be a priority.

Having friends and family as part of one’s life is also important to the young adults with intellectual disabilities’ sense of belonging yet many note that their friends are not part of their everyday activities. Some report keeping in touch with friends and family who are living in other places via the internet. Developmental service agency staff are frequently identified as friends/confidantes. For most, a greater availability of social interaction does not mean they will judge their social integration as adequate. Some who report a lot of social interaction with others

\[\text{20} \text{ The latter could be due to the fact that the level of education in the towns included in the study is relatively low (only 9 to 17% have some University education).}\]

\[\text{21} \text{ Of note is the low participation in the labour force in the towns included in the study (18 to 59% versus the provincial average of 67%).}\]
in town feel their social integration is inadequate, while some who report few opportunities for social interaction judge it to be adequate. This discrepancy appears to be a reflection of both the differences in need for social interaction across individuals and differences in the quality of social interactions.

Being supported; feeling that people in the town are willing to help others is a quality of their towns that most young adults with intellectual disabilities recognize and value. For them, being socially included appears to be less about places one goes to or roles one assumes and more about having people in one’s life. This means opportunities for social interactions with others which for the most part are provided by the local developmental service agency. The reliance on these service providers compensates, in part, for the general lack of spaces and structures for young adults in rural communities generally (including transportation). There is a sense that the youth in general have been neglected as the towns have focused on providing services and activities to their aging population.

Young adults with intellectual disabilities tend to be poor, have low levels of education and be unemployed. In this regard, they are similar to the majority of residents in the towns studied. However, some present with physical limitations, communication impairments and/or maladaptive behaviours. When these are present or when the town’s demographic profile changes with the in-migration of professionals from urban centers, differences are more pronounced. Perceptions of similarity are important to sense of belonging and social inclusion. Otherness is subjective. It is the subjective perceptions of self and others that are important, not absolutes based solely on objective criteria like characteristics of the person.
How Do the Perspectives of Young Adults with Intellectual Disabilities on Sense of Community Differ from that of their Caregivers and Other Community Members?

Previous research related to social inclusion of individual with intellectual disabilities has failed to examine critically the forces shaping experiences and perceptions. The findings related to differences in responses to the Sense of Community Scale between groups and across towns point to some of these forces or factors.

One such force relates to meanings that persons living with a disability (self or family member) ascribe to the practices they observed. A town’s generous responses to disasters and need (e.g., the ice storm, house fires, floods, high medical costs) give them faith that residents of the town are willing to help others in need (including themselves). This element contributes greatly to their sense of community.

As noted in the previous section, perceptions of similarity are important for sense of belonging and social inclusion but they are particularly important for young adults with intellectual disabilities. If few residents of the town have achieved post-secondary education, many are unemployed, and income levels are low, young adults with intellectual disabilities will report more similarity and report a greater sense of community.

Other elements such as daily interaction with friends contribute more to sense of community of other community members than to that experienced by young adults with intellectual disabilities. It appears not to be due to a lack of desire for such contacts but to a resignation to the reality that such interactions are not an integral part of one’s life and therefore one’s sense of community needs to be drawn from other elements as described above. Friends
do not tend to be part of their everyday lives. They must often rely on others to assist them in maintaining friendships (e.g., providing transportation, activities). The internet may be changing the ease with which young adults with intellectual disabilities can remain engaged with friends even in the same town. Some include paid workers and family members among their friends.

**What is the Impact of Context on Sense of Community among Young Adults with Intellectual Disabilities in Rural and Small Town Ontario?**

Findings from the three towns suggest three unique dynamics at play. These related to (1) differential experience of community boundaries, (2) the impact of socio-demographic shifts, and (3) notions of community.

From Town C, the differential experience of boundaries is revealed. Proximity to urban centers, is an important geographical feature to consider when examining rural communities. When a significant proportion of the town residents access employment, social and recreational opportunities as well as health and other services in a nearby city, others with or without intellectual disabilities who lack the independence (transportation or otherwise) to expand their community boundary will be dissatisfied knowing they are missing out.

Significant socio-demographic shifts are seen in some rural areas as the appeal of rural tranquility and beauty brings professionals and other former city dwellers to take up residence. This significant in-migration results in a greater sense of difference among residents including adults with intellectual disabilities. This was the case for Town A.

In Town B where the participants report a loss of contact with friends with the transition from school, where transportation is identified as a barrier to social inclusion and where the
internet is used to support social connections, young adults with intellectual disabilities are less likely to report that their friends are part of their daily lives. They nevertheless report the highest scores on the Sense of Community Scale. In this town, the role of the local developmental service agency is significant in providing not only venues for interaction but also a sense of family and friendships to young adults with intellectual disabilities. The agency offers a community within the larger community.

Summary of Key Findings

The experience of community is affected by spaces and structures and their proximity. (Key Finding #1)

For the young adults with intellectual disabilities interviewed, the local developmental service agency is a key context variable relevant to understanding their experience of social inclusion and sense of belonging. (Key Finding #2)

Community involvement is easier for those seen as similar and sense of community is stronger among those who see themselves as similar. (Key Finding #3)

Residents of a small town who have a greater need for supports derive more sense of community from knowing that other residents are willing to help those in need. (Key Finding #4)

Young adults with intellectual disabilities are less likely to derive sense of community from daily interactions with friends. (Key Finding #5)

Different forces contribute to sense of community among young adults with intellectual disabilities in different towns. (Key Finding #6)

Satisfaction with community belonging may be dependent on the contribution of connections outside the community of place (town). (Key Finding #7)

Proximity to larger centers may emphasize disadvantage. (Key Finding #8).
Contribution to Knowledge, Theory and Public Policy

The key findings add to the limited body of research related to the experiences of individuals with intellectual disabilities in rural communities. While no comparisons are made to other groups within the same towns or to individuals with intellectual disabilities in urban areas, the study highlights how factors other than the attributes of the individuals with intellectual disabilities are influential including spaces/structures (venues within the town), practices (role of the local developmental service agencies, connecting via internet), and meanings (similarity).

The findings contribute to a deeper understanding of what Laws and Radford (1998) refer to as the “duality” of the experiences of persons with intellectual disabilities which are at once similar to and different from those of other citizens. It is clear from the findings that difference is felt among some young adults with intellectual disabilities but supported difference can lead to belonging and satisfaction even if segregation from mainstream community results for some aspects of one’s life (social, recreational). There remains a sense that “the community is there for me”. The importance of recognizing difference and supporting it is also inherent in Walker (1999)’s finding that promoting accommodation increases people’s sense of place and community connections.

Liepins’ framework should be enhanced to include an outer layer or third dimension to depict the relative importance of surrounding towns/cities and of virtual connections (e.g., via internet) to the experience of social inclusion and belonging among young adults with intellectual disabilities in rural and small town Ontario.
The findings draw attention to shifts in population demographics and how these can impact on the experiences of young adults with intellectual disabilities through the lack of attention to spaces/structures and practices to engage young people as emphasis is placed on meeting the needs of the elderly or other taxpayers. Policy makers must recognize that belonging and community from the perspective of young adults with intellectual disabilities may not mean inclusion in all that mainstream community offers if it is not geared to their age group, interests or abilities. As the number of young adults without disabilities in rural and small town communities in Ontario drops, segregated social and recreational activities contribute to belonging and community satisfaction among young adults with intellectual disabilities. While the community may perceive these formal supports as a barrier to knowing the needs of the individual, individuals with intellectual disabilities and their families include local developmental service agencies as a dominant feature in their community.

There is a need to create spaces/structures for common and simultaneous use by different groups within the towns. Young adults with intellectual disabilities should be offered the opportunity to contribute to the many activities to help others in the town thereby enhancing their sense that others rely on them as they rely on others (reciprocity). Continued community awareness/visibility is also important; awareness of individuals and their needs may be more important than awareness of the service provider and its needs (e.g., for board members or money).
Strengths and Limitations of the Study

The major strength of this study was its ability to consider the nature of specific towns on the experiences of young adults with intellectual disabilities by employing a case study approach with towns as the unit of analysis and persons with intellectual disabilities embedded in those towns. This ensured the focus remained on the context rather than on the attributes of the young adults with intellectual disabilities. Liepins’ theoretical framework further encouraged this focus on context.

Using hermeneutical phenomenology allowed for the fusion of horizons (development of understanding) by combining multiple perspectives and sources of information systematically. This was particularly valuable given the contested nature of community and to a certain extent rurality and the aim of developing an understanding of experience rather than measuring social inclusion against an objective benchmark.

An ethnographic component (spending time living in the towns alongside young adults with intellectual disabilities) would have enhanced the ability to uncover practices and meanings which are more difficult to share in interviews. However, hermeneutics’ textual analyses of diverse voices (young adult with intellectual disabilities, their caregivers, other community members) provided a rich source of information given the challenges of interviewing individuals with intellectual disabilities (e.g., acquiescence, brevity and concreteness of responses) and a form of triangulation.

The participants were all volunteers. The young adults with intellectual disabilities were identified first by the local developmental service agency exclusively. Other participants were
also initially identified by the agency but others were identified by participants. The experiences reported are those of the participants and may not reflect the experiences of others in the same town. In particular, the experiences of young women with intellectual disabilities in Town C are not well represented as only one participant was a woman. Despite this lack of representation in one town, across the three towns, the experiences of a diverse group of young adults with intellectual disabilities was captured along with the perspectives of a variety of community members.

Conclusions

Community and social inclusion for young adults with intellectual disabilities in rural and small town Ontario appears to be paradoxical. The current study suggests that formal support (specialized services directed at persons with intellectual disabilities) is a mediating factor. These supports contribute to a sense of belonging to a sub-community as well as the community as a whole while providing for segregated activities. From a civil liberty perspective, social segregation is problematic if forced; however, can it ever be said to be a choice for a historically marginalized group?

Perhaps the answer is in the way service providers engaged in supporting young adults with intellectual disabilities interact with the community and present their clients and their needs to the community. These practices are important contributors to community attitudes (meanings) and behaviours (practices) towards the young adults with intellectual disabilities. Inclusion can be fostered by inviting the community 'in' to service structures and spaces as well as placing the marginalized 'in' the structures and spaces of the broader community.
Being seen and known is such an integral part of belonging in a small town or rural setting. Young adults with intellectual disabilities need and want to be seen and known in their towns. Many yearn for more interactions with friends – those who share common interests. Inclusion requires opportunities for sharing not only spaces and structures but also interests.

It takes a sense that the town cares for young adults with intellectual disabilities to feel that they belong. Caring can be in the form of specialized supports provided. It does take a village, but that village includes specialized supports.

The Ontario government’s view that “with the right services and supports, people with intellectual disabilities in Ontario can participate fully in community and feel that they truly belong” is partly supported by this thesis. It takes the supports provided by local developmental service agencies for young adults with intellectual disabilities to be socially included (as measured by satisfaction with community belonging) in rural and small town Ontario. However, it also requires, as Reinders (2002) noted, attention to the politics of culture. Our towns need to be infused with the value of community.

In conclusion, in a small town or rural community, it takes opportunities to fully engage with all the community has to offer for young adults with intellectual disabilities to be socially included. In creating these opportunities, all the community's resources including its natural surroundings should be exploited to create shared experiences with a variety of other residents. For young adults with intellectual disabilities to be socially included, it also takes being valued enough to have one’s needs recognized and supported. As Laws and Radford (1998) cautioned researchers, so too should community members, service providers and policy makers be
reminded to “hold the dual notion of the lives and experiences of disabled people as similar AND different to non-disabled people’s lives”. 


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Appendix A: Queen’s University Research Ethics Board Certificate
Queen's University, in accordance with the “Tri-Council Policy Statement, 1998” prepared by the Medical Research Council, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada requires that research projects involving human subjects be reviewed annually to determine their acceptability on ethical grounds.

A Research Ethics Board composed of:

- **Dr. A.F. Clark**
  Emeritus Professor, Department of Biochemistry, Faculty of Health Sciences, Queen's University (Chair)

- **Dr. S. Burke**
  Emeritus Professor, School of Nursing, Queen's University

- **Rev. T. Deline**
  Community Member

- **Dr. M. Evans**
  Community Member

- **Dr. M. Green**
  Assistant Professor, Department of Family Medicine, Queen's University

- **Mr. C. Kenny**
  Community Member

- **Dr. J. Low**
  Emeritus Professor, Department of Obstetrics and Gynaecology, Queen's University and Kingston General Hospital

- **Dr. H. Murray**
  Assistant Professor, Department of Emergency Medicine, Queen's University

- **Dr. W. Racz**
  Emeritus Professor, Department of Pharmacology & Toxicology, Queen's

- **Dr. H. Richardson**
  Assistant Professor, Department of Community Health & Epidemiology Project Coordinator, NCIC CTG, Queen's University

- **Dr. B. Simchison**
  Assistant Professor, Department of Anesthesiology, Queen's University

- **Dr. A.N. Singh**
  WHO Professor in Psychosomatic Medicine and Psychopharmacology Professor of Psychiatry and Pharmacology Chair and Head, Division of Psychopharmacology, Queen's University

- **Dr. S. Taylor**
  Director, Office of Bioethics, Queen's University and Kingston General Hospital; Associate Professor, Department of Medicine, Queen's University

- **Ms. K. Weisbaum**
  LL.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)

has examined the protocol (April 23, 2006), Individual with ID Interview Guide, Family Member Interview Guide, Scales of Independent Behavior-Revised, and revised consent forms for the project entitled "Rural and Small Town Southeastern Ontario - Places for Young Adults with Intellectual Disabilities" as proposed by Dr. H. Ouette-Kuntz of the Department of Community Health and Epidemiology and the Department of Geography at Queen's University and considers it to be ethically acceptable. This approval is valid for one year. If there are any amendments or changes to the protocol affecting the subjects in this study, it is the responsibility of the principal investigator to notify the Research Ethics Board. Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.”

Chair, Research Ethics Board

Original to Investigator - Copy to Department Head - Copy to Hospital(s) - P&T - File Copy

EPID-228-06
2006-05-08

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Appendix B: Information Letter and Consent Form – Young Adults with Intellectual Disabilities
You are invited to participate in a study directed by me (Hélène Ouellette-Kuntz). I teach at Queen’s University and I am also a student there. This study is part of a program that I lead funded by the government in Ottawa. It is called the Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities (www.seocura.org). The study is also my PhD thesis.

The study is about what it is like for young adults with intellectual disabilities living in small towns and rural areas in Southeastern Ontario. To learn about this, I want to talk with you, your family and other people in your town. I will be asking you questions about where you work, what you do for fun, and who you do things with. This will take about an hour. I would like to meet with you somewhere in your community like a library, a restaurant or a place you go to meet other people. I will record our talk using a voice recorder so that I can listen to it later to make sure I do not miss anything you say. I might have to contact you again if something was not clear or if I need more information.

It is your choice if you want to do this. It will not affect the help you get from your community. If you do choose to do this, you will be free to change your mind at any time. Some of the questions I will be asking you are personal and may be upsetting to you. You do not have to answer any questions you do not want to answer.

I am the only person who will know your answers. I will use a code instead of your name when I tell others about your answers. I will also use a code instead of naming your town. Five years after the study is done, I will shred the papers and erase the voice recordings. The only time, I would have to tell someone else something you tell me is if something you say makes me think you might hurt yourself or someone else of that someone else might have hurt you.
What I learn from this study will be submitted as a thesis to Queen’s University and kept in the library. I will also use parts of it for publication in academic journals and reports to partners of the SEO CURA in ID. Some of these reports might be posted on our website (www.seocura.org). The results will also be presented at meetings.

Those who speak with me for this project can receive $15.00. To receive this, you will have to let me know your Social Insurance Number so that I can ask the University to send you a cheque.

By signing your name at the bottom of this page, you are telling me that you

1. have read this letter of information and/or had it explained to you, that all your questions have been satisfactorily answered, and that you will keep a copy of this letter for your records

2. want to meet with me for about an hour so that I can ask you my questions and record our conversation

3. agree that I can contact you again if I need to check something with you

4. understand that your participation is voluntary/your choice and that you can stop being involved at any time

5. understand that I will be the only person who will know your answers

6. know that you can contact me, my thesis supervisor, my Department Heads, or the Chair of the Research Ethics Board at Queen’s by phone or email if you have any questions or concerns

   • Me: Ms. Hélène Ouellette-Kuntz, 613-548-4417 extension 1198 or 1-866-656-4417 extension 1198; oullette@post.queensu.ca
   • My thesis Supervisor: Dr. Mark Rosenberg, 613-533-6046; rosenber@post.queensu.ca

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• My Department Heads: Dr. Bill MacKillop, Dept. of Community Health & Epidemiology, 613-533-2091; William.Mackillop@krcc.on.ca OR Dr. Anne Godlewska, Dept. of Geography, 613-533-2903; godlewsk@post.queensu.ca

• The Chair of the Research Ethics Board at Queen’s: Dr. Albert Clark, 613-533-6081; clarkaf@post.queensu.ca

Name: ___________________________ Signature: ______________________________

Date: _______________________ Social Insurance Number: ______________________

________________________________________________________________________

OPTIONAL: I may want to use some examples of what people say in presentations. Could I use parts of our recorded conversation in such a presentation?

By initialing this statement below,

_____ I give you permission to use my recorded voice in presentations.

________________________________________________________________________

STATEMENT OF INVESTIGATOR:

I have carefully explained to the participant the nature of the above research study. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

__________________________________________  _________________
Signature of Principal Investigator  Date
Appendix C: Information Letter and Consent Form – Family Members
You are invited to participate in a study directed by me (Hélène Ouellette-Kuntz). I teach at Queen’s University and I am also a student there. This study is part of a program that I lead funded by the government in Ottawa. It is called the Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities (www.seocura.org). The study is also my PhD thesis.

The study is about what it is like for young adults with intellectual disabilities living in small towns and rural areas in Southeastern Ontario. To learn about this, I want to talk with young adults with intellectual disabilities between 18 and 24 years of age, their families and other people in the different towns. I would like to ask you, as a family member, what you can tell me about what it is like for young adults looking for work, recreational and social activities in your town. This will take about an hour. I would like to meet with you somewhere in your community like a library, a restaurant or a place you go to meet other people. I will record our talk using a voice recorder so that I can listen to it later to make sure I do not miss anything you say. I might have to contact you again if I something was not clear or if I need more information.

It is your choice if you want to do this. It will not affect the services and supports you or your family member receive. If you do choose to do this, you will be free to change your mind at any time. Some of the questions I will be asking you are personal and may be upsetting to you. You do not have to answer any questions you do not want to answer.

I am the only person who will know your answers. I will use a code instead of your name when I tell others about your answers. I will also use a code instead of naming your town. Five years after the study is done, I will shred the papers and erase the voice recordings. The only time, I would have to tell someone else something you tell me is if something you say makes me
think you may be at risk of harming yourself or another or if abuse of a child, or abuse by a helping professional is disclosed.

What I learn from this study will be submitted as a thesis to Queen’s University and kept in the library. I will also use parts of it for publication in academic journals and reports to partners of the SEO CURA in ID. Some of these reports might be posted on our website (www.seocura.org). The results will also be presented at meetings.

Everyone who speaks with me for this project can receive $15.00. To receive this, you will have to let me know your Social Insurance Number so that I can ask the University to send you a cheque.

By signing your name at the bottom of this page, you are telling me that

1. you have read this letter of information and/or had it explained to you, that all your questions have been satisfactorily answered, and that you will keep a copy of this letter for your records
2. you want to meet with me for about an hour so that I can ask you my questions and record our conversation
3. you agree that I can contact you again if I need to check something with you
4. you understand that your participation is voluntary and that you can stop being involved at any time
5. you understand that I will be the only person who will know your answers
6. know that you can contact me, my thesis supervisor, my Department Heads, or the Chair of the Research Ethics Board at Queen’s by phone or email if you have any questions or concerns

- Me: Ms. Hélène Ouellette-Kuntz, 613-548-4417 extension 1198 or 1-866-656-4417 extension 1198; oullette@post.queensu.ca
- My thesis Supervisor: Dr. Mark Rosenberg, 613-533-6046; rosenber@post.queensu.ca
• My Department Heads: Dr. Bill MacKillop, Dept. of Community Health & Epidemiology, 613-533-2091; William.Mackillop@krcc.on.ca OR Dr. Anne Godlewska, Dept. of Geography, 613-533-2903; godlewsk@post.queensu.ca

• The Chair of the Research Ethics Board at Queen’s: Dr. Albert Clark, 613-533-6081; clarkaf@post.queensu.ca

Name: __________________________ Signature: _______________________________

Date: __________________________ Social Insurance Number: ___________________

________________________________________________________________________

OPTIONAL: I may want to use some examples of what people say in presentations. Could I use parts of our recorded conversation in such a presentation?

By initialing this statement below,

_____ I give you permission to use my recorded voice in presentations.

________________________________________________________________________

STATEMENT OF INVESTIGATOR:

I have carefully explained to the participant the nature of the above research study. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

____________________________  ________________
Signature of Principal Investigator  Date

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Appendix D: Information letter and consent form – community member
Letter to Potential Community Member Informants

DATE

Name
Title
Organization
Town, Ontario
Postal Code

Dear Name,

Rural and small town residents are more likely to have a strong sense of belonging to their local communities says a Statistics Canada report. I am interested in learning more about this sense of belonging in rural and small town Southeastern Ontario and how it relates to the inclusion of young adults with intellectual disabilities. [name of partner], of [name of agency] , one of our community partners, tells me you are a key person to speak with about [name of town].

As part of my PhD research under the supervision of Dr. Mark Rosenberg (Departments of Geography and Community Health & Epidemiology, Queen’s University), I am conducting case studies of several communities across Southeastern Ontario including yours. I am planning a 2-3 day visit to [name of town] in [month]. During my visit, I will be speaking with young adults with intellectual disabilities (18-24 years), their families and members of the community.

This research is also part of a larger program of research that I lead funded by the Social Sciences and Humanities Research Council of Canada, the Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities (www.seocura.org). This program includes 41 community partners providing supports to individuals with intellectual disabilities across the region.

I will be calling you in a week or so to tell you more about the project and to discuss the possibility of interviewing you for this study.

Sincerely,

Hélène Ouellette-Kuntz
Doctoral Candidate, Department of Geography, Queen’s University
Associate Professor, Department of Community Health & Epidemiology, Queen’s University
Director, Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities
Script for Telephone Follow-up with Potential Informants

Hello, my name is Hélène Ouellette-Kuntz. May I please speak with <name potential key informant>.

If potential informant is there continue on. If not ask for a preferable day and time to call back and record information.

I am calling to follow-up on the letter I sent you regarding my study of small town and rural Southeastern Ontario and the inclusion of young adults with intellectual disabilities. Do you remember receiving it?

If no, go over the Letter of Introduction before continuing.

If yes, continue…

I will be in <name of town> on <date> and I was hoping to meet with you to tell you more about the project and to ask you a few questions about your town. This will take 30 minutes to an hour. Would it be possible to set up a time to meet?

Answer any questions and record preferred interview date, time and place.

Thank you. I will send you a copy of the consent form that you will be required to sign as well as a sample of questions that I will be asking you so that you can be prepared for the interview. I look forward to speaking with you on <date>. Have a good day.

If the individual is unwilling or not available, ask if he/she might recommend someone else.

Thank you for your time. Have a good day.
**Information Sheet and Consent Form – Community Members**

**TITLE OF PROJECT: Rural and Small Town Southeastern Ontario – Places for Young Adults with Intellectual Disabilities**

You are invited to participate in a study examining the experiences of young adults with intellectual disabilities living in rural and small town Southeastern Ontario. This study is part of a program of research funded by the Social Sciences and Humanities Research Council of Canada called the Southeastern Ontario Community-University Research Alliance in Intellectual Disability (www.seocura.org). The study will also fulfill the thesis requirement for my Doctoral thesis in the Department of Geography at Queen’s University.

The project involves comparing different communities including yours. I will be interviewing young adults with intellectual disabilities between 18 and 24 years of age, their families and other people in a the different towns selected across Southeastern Ontario. I would like to ask you, as a member of the community, what you can tell me about what it is like for young adults looking for work, recreational and social activities in your town. I would also like to know what it is generally like to live here; how people relate to each other and what opportunities exist. This will take about an hour. I could come to your office or meet you somewhere in your community like a library or a restaurant. I will record our talk using a voice recorder so that I can listen to it later to make sure I do not miss anything you say. I might have to contact you again if I something was not clear or if I need more information.

Your participation is voluntary. If you do choose to participate, you will be free to withdraw at any time and answer only the questions you feel comfortable answering.

Your answers will be kept strictly confidential. I will use a code instead of your name. I will also use a code instead of naming your town. Five years after the study is done, I will shred the papers and erase the voice recordings. The only time, I would have
to tell someone else something you tell me is if abuse of a child, or abuse by a helping
professional is disclosed.

What I learn from this study will be submitted as a thesis to Queen’s University
and kept in the library. I will also use parts of it for publication in academic journals and
reports to partners of the SEO CURA in ID. Some of these reports might be posted on
our website (www.seocura.org). The results will also be presented at meetings.

By signing your name at the bottom of this page, you are telling me that
you have read this letter of information and/or had it explained to you, that all your
questions have been satisfactorily answered, and that you will keep a copy of this letter
for your records

you want to meet with me for about an hour so that I can ask you my questions and
record our conversation you agree that I can contact you again if I need to check
something with you

- understand that your participation is voluntary and that you can stop being
  involved at any time
- understand that I will be the only person who will know your answers
- know that can you contact me, my thesis supervisor, my Department Heads, or the
  Chair of the Research Ethics Board at Queen’s by phone or email if you have any
  questions or concerns.

Me: Ms. Hélène Ouellette-Kuntz, 613-548-4417 extension 1198 or 1-866-656-4417
extension 1198; oullette@post.queensu.ca

My thesis Supervisor: Dr. Mark Rosenberg, 613-533-6046; rosenber@post.queensu.ca

My Department Heads: Dr. Bill MacKillop, Dept. of Community Health &
Epidemiology, 613-533-2091; William.Mackillop@krcc.on.ca OR Dr. Anne Godlewska,
Dept. of Geography, 613-533-2903; godlewsk@post.queensu.ca
The Chair of the Research Ethics Board at Queen’s: Dr. Albert Clark, 613-533-6081; clarkaf@post.queensu.ca

Name: __________________________ Signature: __________________________

Date: __________________________

________________________________________________

OPTIONAL: I may want to use some examples of what people say in presentations. Could I use parts of our recorded conversation in such a presentation?

By initialing this statement below,

_____ I give you permission to use my recorded voice in presentations.

________________________________________________

STATEMENT OF INVESTIGATOR:

I, have carefully explained to the participant the nature of the above research study. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

____________________________  _________________
Signature of Principal Investigator  Date
Appendix E: Interview Guide for Young Adults with Intellectual Disabilities
**General Questions**

1. How long have you lived in <name of town>?

2. What do you do in <name of town>? Are you involved on any committees or in any organizations?

3. Tell me about <name of town>. What makes it special? Different from other places?

4. What are the main activities here (work and leisure)?

5. Do people work and play here or do they tend to leave <name of town> for work? for leisure and recreation?

6. What can you tell me about how people with intellectual disabilities are treated in your town? What services are available to you and others?

7. Do young adults like you work in <name of town>? Where do they work?

8. What do you and others do for fun?

**Participation in the local community**

1a. Do people here think of themselves as part of the local area? Do you?

**Reciprocity**

4a. Do people do and receive favours from others living nearby? Do you?

5a. Do local people look after each other? Do you look after others?

6a. Who do people turn to for advice or to share good news? Who do you turn to?

**Feelings of trust and safety**

7a. Do people feel safe in their own home? or going out at night? Do you?
8a. Do you know someone who has been a victim of a crime?

9a. Can people around here be trusted?

**Social connections**

10a. Do people chat with family, friends or neighbours regularly? Do you?

11a. Do people generally have close friends round here? Do you?

12a. Do people tend to go outside this area to visit their friends? Do you?

**Citizen power**

13a. Do people formally complain about local services? Have you?

14a. Have people in the community formed committees to fight local causes? Have you?

**Community perception**

15a. Do people generally enjoy living here? Do you?

16a. Are there enough community facilities and public transportation?

**Sense of Community Scale** (adapted from Nasar & Julian, 1995) using gradient of agreement scale from NO no no/yes yes YES, ask participant to rate each items on a 5 point scale to show level of agreement. Participants may choose to point to their response rather than say it aloud.

1. I am quite similar to most people who live here.

2. If I feel like talking, I can generally find someone in this town to talk to right away.

3. I DON’T care whether this town does well.
4. The police in this town are generally friendly.

5. People here know they can get help from others in the town if they are in trouble.

6. My friends in this town are part of my everyday activities.

7. If I am upset about something personal, there is NO ONE in this town to whom I can turn.

8. I have NO friends in this town on whom I can depend.

9. If there were a serious problem in this town, the people here could get together to solve it.

10. If someone does something good in this town, that makes me feel good.

11. If I had an emergency, even people I do not know in this town would be willing to help.
General Demographic Information

1. When is your birthday? What year? What month?
   
   year ________  □ Don’t know
   
   month ________  □ Don’t know

2. How old are you? ________________  □ Don’t know

3. Where were you born? (town/city) ________________________  □ Don’t know
   
   (province/state) __________  □ Don’t know
   
   (country, if other than Canada) ____________________________  □ Don’t know

4. When did you leave school? ________________  □ Don’t know

5. What are you doing now instead of school? ______________  □ Don’t know

6. What do you like best about this?

   _______________________________________________________
   
   □ Don’t know

Observation information, do not ask: 7. Gender: □ Male  □ Female
Interviewer Instructions: This instrument is used to rate the student’s sense of belonging in three areas (physical, social, community) with regard to “importance” and “satisfaction”. The questions in bold type are root questions for the topic, but are not to be read to the student. Use the italicized statement and questions in the text boxes to prompt the student’s thinking about things related to the numbered questions. Use the space provided to make notes about his or her responses. When the student has responded to all questions in the text box, THEN ask the numbered questions. Use the “rating scale prompt” card as needed. Rate and record the student’s response in the box next to each item using the rating scale provided. If unable to make a rating, code the box with “NR” (Not Rated). After each section, if half or more of the items were NT, TERMINATE interview (go to page 30).

1--------------------------2---------------------3---------------------4----------------------5

VERY LITTLE  A LITTLE  SOME  QUITE A BIT  A LOT

PHYSICAL BELONGING

How important to you is where you live?
How satisfied are you with where you live?

Tell me about the place you live.
Do you have your own room?
Do you have your own bathroom?
Is there a television where you live?
What rooms are in your house/apartment?
What do you like about where you live?
What do you NOT like about where you live?

Notes:_________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

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1. Do you care where you live? How much?

2. Do you like where you are living? How much?

**How important to you is having space for privacy?**
**How satisfied are you with your space for privacy?**

<table>
<thead>
<tr>
<th>Do you have a place where you can be alone?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have your own room?</td>
</tr>
<tr>
<td>Do you get to say when other people can come into your room?</td>
</tr>
</tbody>
</table>

Notes:_________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

3. Do you care about having your own space? How much?

4. Are you happy with the space you have to be alone? How happy?

**How important to you is the neighborhood you live in?**
**How satisfied are you with the neighborhood you live in?**

<table>
<thead>
<tr>
<th>Tell me about your neighborhood.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel at home in your neighborhood?</td>
</tr>
</tbody>
</table>

Notes:_________________________________________________________________
______________________________________________________________________
______________________________________________________________________

5. Do you care what area you live in? How much?
6. Are you happy with living in this area? How happy?

1--------------------------2---------------------3---------------------4----------------------5
VERY LITTLE    A LITTLE    SOME    QUITE A BIT    A LOT

SOCIAL BELONGING

How important to you is having a spouse or special person?
How satisfied are you with having/not having a spouse or special person?

Do you have a special person who you care about a lot?  
Do you have a special person like a boyfriend or girlfriend?  
Tell me about your boyfriend/girlfriend/partner.  
In the future, do you think you might want to meet or live with someone special?

Notes:_________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

7. Do you care about having a husband/wife/partner? How much?

8. Are you happy with having/not having a husband/wife/partner? How happy?
How important to you is being close to people in your family?  
How satisfied are you with your closeness to people in your family?

Tell me about the people in your family -- parents, brothers, sisters.  
How often do you see them? Do you like to see them?  
Do you have any cousins, aunts, uncles, or grandparents?  
How often do you see them? Do you like to see them?  
Do you feel like an important member of the family?

Notes:_________________________________________________________________  
______________________________________________________________________  
______________________________________________________________________  
______________________________________________________________________  
______________________________________________________________________

8. How important to you are the people in your family?

9. Are you happy with your family? How happy?

_______________________________________________________  
1--------------------------2---------------------3---------------------4----------------------5  
VERY LITTLE   A LITTLE      SOME      QUITE A BIT     A LOT  

How important to you is having friends?  
How satisfied are you with the friends you have?

Tell me about your friends. What friends do you have?  
How often do you spend time with your friends?  
What do you do with your friends when you're together?  
Do you have a best friend?  
Would you like to have more friends? Less friends?

Notes:_________________________________________________________________  
______________________________________________________________________  
______________________________________________________________________  
______________________________________________________________________
11. Do you care about having friends? How much?

12. Are you happy with your friends? How happy?

COMMUNITY BELONGING
How important to you is going to school?
How satisfied are you with going to school?

Tell me about your school.
Do you like school?
Do other people who live around you/on your street go to this school?

Notes:_________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

13. Is it important to you to be able to go to school? How important?

14. Are you happy with being able to go to school? How happy?

1--------------------------2---------------------3---------------------4----------------------5
VERY LITTLE   A LITTLE    SOME   QUITE A BIT    A LOT

How important to you is having access to meaningful work?
How satisfied are you with your access to meaningful work?

Do you have a job? [IF NOT, GO TO NEXT TEXT BOX AND SKIP THIS ONE]
Was it easy for you to get a job?
What would you do if you wanted a better job?

Notes:_________________________________________________________________
______________________________________________________________________
______________________________________________________________________
15. Is it important to you to be able to have a job? How important?

16. Are you happy with the kinds of jobs you could get? How happy?

Would you like to have a job?
Could you have a job if you wanted one?

Notes:_________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

17. Is it important to you to be able to have a job? How important?

How important to you is going to places in your community?
How satisfied are you with the places to go in your community?

Tell me about the places you go near your home.
Do you ever go to restaurants? A shopping mall? A park? Why or why not?
When you go to these places, do you feel welcome?

Notes:_________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

18. Do you care if you can go to these places? How much?

19. Do you like going to these places? How much?
Interview Schedule for Social Interaction (ISSI)

Client Version
Adapted from: Academic Press Australia

**Interviewer Instructions:** The ISSI is designed to obtain information about the student’s social interaction. Remember to follow ALL the administration instructions for this instrument. Once you have completed administration of this instrument, take a quick look to see if all applicable items have been answered. Keep in mind that the interviewee has the right to refuse to respond to any and all items.

**Instructions to the Interviewee:**
*I want to get some idea of the people in your life. This includes those you are closest to — family, friends and neighbours — all the people you may meet from day to day.*

1. These days, how many people with similar interests to you do you have contact with? **[Pause, if no answer, randomly prompt using categories.]**

   None .............................................. 1
   1-2.................................................. 2
   3-5.................................................. 3
   6-10................................................. 4
   11-15.............................................. 5
   More than 15.................................... 6
   Not coded ....................................... 7

2. Would you like more or less of this? **[Pause, if no answer, add] or is it about right? (persons, duration or frequency)**

   Less ............................................... 1
   About right...................................... 2
   Depends on the situation.................... 3
   More.............................................. 4
   Not coded....................................... 7
3. In an ordinary week, how many people who you know would you say you have contact with? [Pause, if no answer, randomly prompt using categories.]

None .............................................. 1
1-2.................................................... 2
3-5.................................................... 3
6-10................................................... 4
11-15............................................... 5
More than 15................................. 6
Not coded .................................. 7

4. Would you like more or less of this? [Pause, if no answer, add] or is it about right for you? (persons, duration or frequency)

Less ............................................... 1
About right........................................ 2
Depends on the situation................ 3
More.................................................. 4
Not coded........................................ 7

5. At present, do you wish there were more, or less or are there about the right number of people in your day-to-day life? [Note: focus on extent of social contact (all contacts) not number of contacts.]

Less ............................................... 1
About right........................................ 2
Depends on the situation................ 3
More.................................................. 4
Not coded........................................ 7
6. How many friends do you have who could come to your home at any time and be OK with things as they find them – they wouldn’t be embarrassed if the house were a mess or you were in the middle of a meal.  [Pause, if no answer, prompt sequentially going one above ‘YES’.]

   |          | 1 |
---|----------|---|
None | 1        |
1-2  | 2        |
3-5  | 3        |
6-10 | 4        |
11-15| 5        |
More than 15 | 6 |
Not coded | 7 |

7. Would you prefer more or less of this?  [Pause, if no answer, add] or is it about right for you?

   |          | 1 |
---|----------|---|
Less | 1        |
About right | 2 |
Depends on the situation | 3 |
More | 4        |
Not coded | 7 |

8. Among your family and friends, how many people are there who are immediately available to you, who you can talk with about anything, without having to watch what you says?  [Pause, if no answer, prompt sequentially going one above ‘YES’.]

   |          | 1 |
---|----------|---|
None | 1        |
1-2 | 2        |
3-5 | 3        |
6-10 | 4       |
11-15 | 5 |
More than 15 | 6 |
Not coded | 7 |
9. Would you like to have more or less people like this? [Pause, if no answer, add] or is it about right for you?

- Less ............................................... 1
- About right ..................................... 2
- Depends on the situation .................... 3
- More ............................................... 4
- Not applicable .................................. 9
- Not coded ....................................... 7

10. With the one (those) you have, would you like to feel more free to be frank? [Pause, if no answer, add] or is it about right?

- About right ..................................... 1
- Depends on the situation .................... 2
- More free ........................................ 3
- Not applicable .................................. 9
- Not coded ....................................... 7

11. Is there any particular person you feel you can lean on?

- No one ............................................ 1
- Yes, but doesn’t need anyone .......... 2
- Yes .................................................. 3
- Not coded ....................................... 7

12. Would you like to be able to lean more or less on ___________________?

- Less ............................................... 1
- About right ..................................... 2
- Depends on the situation .................... 3
- More ............................................... 4
- Not applicable .................................. 9
- Not coded ....................................... 7
13. Would you like to have someone else like this? [Pause, if no answer, add] or is he/she enough?
   Yes ........................................... 1
   Don’t know .................................... 2
   Enough ......................................... 3
   Not applicable ................................. 9
   Not coded ...................................... 7

14. Do you feel there is one particular person who feels very close to you?
   No one .......................................... 1
   Not sure ......................................... 2
   Yes .................................................. 3
   Not coded ......................................... 7

15. Would you like ________ to feel closer, or not so close to you, or is it about right the way it is?
   Closer ........................................... 1
   About right ...................................... 2
   Depends on the situation ..................... 3
   Not so close ..................................... 4
   Not applicable ................................... 9
   Not coded ......................................... 7

16. Would you like to have more or fewer people like this? [Pause, if no answer, add] or is this about right?
   Fewer ........................................... 1
   About right ...................................... 2
   More ............................................... 3
   Not applicable ................................... 9
   Not coded ......................................... 7

17. When you are happy, is there any particular person you can share it with – someone who you feel sure will feel happy simply because you are?
   No one ........................................... 0
   Yes .................................................. 1
   Not coded ......................................... 7
18. Would you like to feel this more with ___________? [Pause, if no answer, add] or is it about right?

<table>
<thead>
<tr>
<th>Option</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>About right</td>
<td>1</td>
</tr>
<tr>
<td>More</td>
<td>3</td>
</tr>
<tr>
<td>Not applicable</td>
<td>9</td>
</tr>
<tr>
<td>Not coded</td>
<td>7</td>
</tr>
</tbody>
</table>

19. Would you like to have someone else like this? [Pause, if no answer, add] or is this enough?

<table>
<thead>
<tr>
<th>Option</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
</tr>
<tr>
<td>Enough</td>
<td>3</td>
</tr>
<tr>
<td>Not applicable</td>
<td>9</td>
</tr>
<tr>
<td>Not coded</td>
<td>7</td>
</tr>
</tbody>
</table>

20. At present, do you have someone you can share your most private feelings with (confide in)?

<table>
<thead>
<tr>
<th>Option</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>No one</td>
<td>0</td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>Not coded</td>
<td>7</td>
</tr>
</tbody>
</table>

21. Do you wish you could share more with ___________? [Pause, if no answer, add] or is it about right?

<table>
<thead>
<tr>
<th>Option</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>About right</td>
<td>1</td>
</tr>
<tr>
<td>Depends on the situation</td>
<td>2</td>
</tr>
<tr>
<td>More</td>
<td>3</td>
</tr>
<tr>
<td>Not applicable</td>
<td>9</td>
</tr>
<tr>
<td>Not coded</td>
<td>7</td>
</tr>
</tbody>
</table>

22. Would you like to have someone else like this as well? [Pause, if no answer, add] would you prefer not to use a confidant, [then add] or is it just about right for you the way it is?

<table>
<thead>
<tr>
<th>Option</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prefers no confidant</td>
<td>1</td>
</tr>
<tr>
<td>About right</td>
<td>2</td>
</tr>
<tr>
<td>Depends on the situation</td>
<td>3</td>
</tr>
<tr>
<td>Like someone else as well</td>
<td>4</td>
</tr>
<tr>
<td>Not applicable</td>
<td>9</td>
</tr>
<tr>
<td>Not coded</td>
<td>7</td>
</tr>
</tbody>
</table>
23. Are there ever times when you are comforted by being held in someone’s arms (hugged)?

   No ................................. 0
   Yes.................................... 1
   Not coded............................ 7

24. Is there anyone you would like to comfort you more in this way? [Pause, if no answer, add] or is it all right the way it is?

   All right as is........................ 2
   Yes..................................... 1
   Not applicable ..................... 9
   Not coded............................ 7

25. Do you think those at home really appreciate what you do for them?

   Yes ................................. 1
   Not really ........................... 2
   Depends on the situation ....... 3
   Not at all ............................ 4
   Not applicable .................... 9
   Not coded........................... 7

26. Would you like any of them to show more appreciation?

   Less ................................. 1
   About right ........................ 2
   Depends on the situation ....... 3
   More ................................. 4
   Not applicable .................... 9
   Not coded........................... 7
27. Are there people around from whom you can easily ask small favours? Such as people you know well enough to borrow tools, things for cooking or games.

No……………………………… 0

Yes—How many? □

Not coded ............................ 7

28. Would you like to have more or less of this? [Pause] or is it about right?

Less ................................. 1
About right ......................... 2
Depends on the situation ........... 3
More ................................. 4
Not coded ............................. 7

29. (Apart from those at home) are there people in (this town) to whom you can turn in times of difficulties? Someone you can see fairly easily whom you could trust and whom you could expect real help from in times of trouble.

No……………………………… 0

Yes—How many? □

Not coded ............................ 7

30. Do you wish you had more of such help available? [Pause] or is it about right?

About right ............................ 1
Depends on the situation ........... 2
More ................................. 3
Not coded ............................. 7
An Investigation of Factors Contributing to Vocational Satisfaction

Are you working now?

*If yes,* Please tell me about what you do at your job.

How many hours a week do you work?

How long have you worked there for?

Do you mind telling me how much you make an hour?

What things do you like about your job? *If more than one job, contrast between jobs*

What things don’t you like about it? Things you would change if you could? *If more than one job, contrast between jobs*

Do you think you will stay at this job? For how long?

*[If a short time]* What would have to happen for you to want to stay longer?

When there’s a problem at work, who do you go to for help? Why?

Do you feel that your work is safe? Is there anything there that could hurt you?

Did anyone give you any training at your job?

*If no,* Please tell me about what you did at your last job.

What things did you like about that job?

What things didn’t you like about it? Things you would have changed if you could?
Why didn’t your last job work out?

Would you have stayed at your last job if you could? *If yes, why? If no, why not?*

Have you had another job that you like better? What did you like about it?

Are you looking for another job now? *If yes, why? If no, why not?*

Since you left school, have you worked anywhere else or done any jobs other than the one’s you just told me about?

*If yes,* Please tell me what you did there.

What things did you like about that job?

What things didn’t you like about that job?

How long did you work there for?

Why did you leave the job?

*If there is a volunteer job,*

How much do you work there?

What do you do at your volunteer job?

What do you like about that job?

What don’t you like?

Why do you continue to volunteer there?

Do you like having several jobs and activities (e.g. volunteering) to go to?

If you could choose one of these jobs or activities to do, which one would it be? Why?
Are there benefits to having these jobs and activities to go to? If yes, what are they?

Are there disadvantages/problems to having these jobs and activities to go to? If yes, what are they?

How did you find your (last) paid job? Did a counsellor help you?

Who decided that this type of work or this job would be good for you? Why did they think it would be good for you?

Do you want to continue in this line of work? What other things do you think you might want to try?

If tomorrow you had a chance to do any job you liked, what would this be? Why? What do you think it would take to make this happen?

_If “dream job” does not match actual job:_ Why are you still working at your current job?

Do you think it is important for people to work? Why or why not?

Why do you want to work? [exclude question if they have indicated no interest in working]

Do you think it is important for people to be paid for work?

_If yes,_ What do you think is a fair wage for people doing your job?

Would you like to make more money if you could? _If yes,_ how would you do this (more hours or higher wage per hour)?

Does anything stop you from working more?

Can you tell me, on a scale of 1 – 10, how happy you are with you job(s)? 1 would be very unhappy, couldn’t be worse, 10 would be very happy couldn’t be any better, and 5 would be not really happy, not really unhappy.
Appendix F: Interview Guide for Family Members/Caregivers
General Demographic Information

Part A - Information about the parent or guardian (person being interviewed).

1. Date of Birth year ________ month __________

2. Place of Birth (town/city) ______________________ (province/state) ___________
   (country, if other than Canada) ____________________________

3. Gender
   1…Male  2…Female

4. Marital Status:
   1… Single  5… Remarried
   2… Married  6… Widowed
   3… Separated  7… Common law partner
   4… Divorced

5. Relationship to person with intellectual disability: 1…Parent  2…Guardian  3…Other
   If other, please state ____________________________

6. Highest Level of Education Completed:
   1…Less than grade 9  6…Community college certificate
   2…Grade 9 (Jr. High School)  7…University degree
   3…Grade 10 or 11 (Partial High School)  8…Some post-graduate training
   4…High School Diploma  9…Graduate or professional degree
   5…Some college (at least one year)

7. Occupation or Job Title: ________________________________

8. Job Description: ______________________________________________________
9. Annual Household Income Range:

1…$25,000 or less  
2…$25,001 - $35,000  
3…$35,001 - $45,000  
4…$45,001 - $55,000  
5…$55,001 - $65,000

6…$65,001 - $75,000  
7…$75,001 - $85,000  
8…$85,001 - $95,000  
9…$95,001 or more

10. Who else lives in the home? Check box if the person has an intellectual disability.

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Gender</th>
<th>Age</th>
<th>Person with ID</th>
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Part B - Information about the person with an intellectual disability.

1. Date of Birth: year ________ month __________

2. Place of Birth: (town/city) ______________________ (province/state) ___________

    (country, if other than Canada) ____________________________

3. Gender:  1… Male  

4. Living Arrangement: ______________________________________

4a. Number of years living in current place: __________
5. Where did the person live before his or her present home? □ N/A

   a) Immediately before: ____________________________________________

   b) Other places before: ____________________________________________

6. Please indicate this individual's intellectual disabilities and/or special needs
   (check all that apply):

   Yes…1  No…2
   a. Autism Spectrum Disorder ______ ______
   b. Down’s Syndrome ______ ______
   c. Fragile X Syndrome ______ ______
   d. Cerebral Palsy ______ ______
   e. Epilepsy/Seizure Disorder ______ ______
   f. Psychiatric Disorder, specify: ______ ______
   g. Behaviour Disorder ______ ______
   h. Mobility (e.g. uses wheelchair) ______ ______
   i. Vision Impairment ______ ______
   j. Hearing Impairment ______ ______
   k. Other: ___________________________ ______ ______

Scales of Independent Behavior – Revised (SiB-R)
(Enclosed Instrument)

Adult AIMS Interview
(Enclosed Instrument)

Sense of Belonging Subscales
Other Person Version
Adapted from: The Quality of Life Profile, Other Person Questionnaire – Short Version
Centre for Health Promotion (1997)

I will read a series of questions that deal with living situation, friends and family, and community. For each question, rate how you think [student’s name] would respond to the question. The rating scale ranges from “1” for “not at all” to “5” meaning “a lot.” Remember that this is your perception of [him/her]. The scale for all of these questions is: [read all the response options to the parent or guardian]

1--------------------------2---------------------3---------------------4----------------------5
NOT AT ALL    A LITTLE  SOME  QUITE A BIT  A LOT

PHYSICAL BELONGING

How important to ________ is:
1. Where [he/she] lives? 
   
2. Having a space for privacy? 
   
3. What neighborhood [he/she] lives in? 
   
How happy is ________ with:
4. Where [he/she] lives? 
   
5. [His/her] space for privacy? 
   
6. The neighborhood [he/she] lives in? 
   


To what extent does ________make [his/her] own decisions about:

7. Where to live?

8. [Her/his] space for privacy?

9. What neighborhood to live in?

To what extent are there opportunities for ________________to:

10. Move if [he/she] wants to?

11. Change [his/her] space for privacy?

12. Move to another neighborhood if
    [he/she] wants to?

1--------------------------2---------------------3---------------------4----------------------5

NOT AT ALL   A LITTLE       SOME       QUITE A BIT       A LOT
SOCIAL BELONGING

How important to ________ is:  13. Having a spouse or special person?

14. Being close to some people in [her/his] family?

15. Having friends?

How happy is ________ with:  16. Having [or not having] a spouse or special person?

17. [his/her] closeness to some people in [his/her] family?

18. [his/her] friends?

To what extent does _____ make [her/his] own decisions about:

19. Having [or not having] a spouse or special person?

20. About spending time with family and friends?
21. Who [his/her] friends are?

To what extent are there opportunities for [________] to:

22. Have a spouse or special person if [he/she] wants to?

23. Spend time with family and friends?

24. Have more or different friends?

1--------------------------2---------------------3---------------------4----------------------5
NOT AT ALL    A LITTLE  SOME  QUITE A BIT  A LOT

COMMUNITY BELONGING

How important to [________] is:

25. Having access to education or training in [his/her] community?

26. Having access to meaningful work in [his/her] community?

27. Going to places in [her/his] community (stores, restaurants, etc.)?

How happy is [________] with:

28. [his/her] access to education or training in [his/her] community?

29. [his/her] access to meaningful work in [her or his] community?
30. The places [he/she] goes to in the community (stores, restaurants, etc.)?

To what extent does _____ make [his/her] own decisions about:

31. Taking courses or training in [his/her] community?

32. Having [or not having] meaningful work in the community?

33. The places [he/she] goes to in the community (stores, restaurants, etc.)?

To what extent are there opportunities for _______ to:

34. Take courses or training in [his/her] community?

35. Have meaningful work in the community?

36. Go to more or different places in [his/her] community?
Interview Schedule for Social Interaction (ISSI)

Other Person Version

Adapted from: Academic Press Australia

**Interviewer Instructions:** The ISSI is designed to obtain information about the student’s social interaction. Remember to follow ALL the administration instructions for this instrument. Once you have completed administration of this instrument, take a quick look to see if all applicable items have been answered. Keep in mind that the interviewee has the right to refuse to respond to any and all items.

**Instructions to the Interviewee:**

I want to get some idea of the people in ____________’s life. This includes those [he/she] is closest to – family, friends and neighbours – all the people _______ may meet from day to day.

1. These days, how many people with similar interests to [him/her] does [he/she] have contact with? [Pause, if no answer, randomly prompt using categories.]

None .............................................. 1
1-2.................................................. 2
3-5.................................................. 3
6-10................................................ 4
11-15.............................................. 5
More than 15.................................... 6
Not coded ...................................... 7
2. Would [he/she] like more or less of this? [Pause, if no answer, add] or is it about right? (persons, duration or frequency)

- Less ............................................... 1
- About right........................................ 2
- Depends on the situation................... 3
- More.................................................. 4
- Not coded....................................... 7

3. In an ordinary week, how many people who [he/she] knows would you say [he/she] has contact with? [Pause, if no answer, randomly prompt using categories.]

- None .............................................. 1
- 1-2.................................................. 2
- 3-5.................................................. 3
- 6-10............................................... 4
- 11-15.............................................. 5
- More than 15................................. 6
- Not coded ...................................... 7

4. Would [he/she] like more or less of this? [Pause, if no answer, add] or is it about right for [him/her]? (persons, duration or frequency)

- Less ............................................... 1
- About right........................................ 2
- Depends on the situation................... 3
- More.................................................. 4
- Not coded....................................... 7
5. At present, does [he/she] wish there were more, or less or are there about the right number of people in [his/her] day-to-day life? [Note: focus on extent of social contact (all contacts) not number of contacts.]

- Less .................................... 1
- About right ......................... 2
- Depends on the situation .......... 3
- More .................................... 4
- Not coded .............................. 7

6. How many friends does [he/she] have who could come to [his/her] home at any time and be OK with things as they find them – they wouldn't be embarrassed if the house were a mess or [he/she] were in the middle of a meal. [Pause, if no answer, prompt sequentially going one above 'YES'.]

- None .................................... 1
- 1-2 ......................................... 2
- 3-5 ......................................... 3
- 6-10 ....................................... 4
- 11-15 ..................................... 5
- More than 15 .......................... 6
- Not coded .............................. 7

7. Would [he/she] prefer more or less of this? [Pause, if no answer, add] or is it about right for [him/her]?

- Less .................................... 1
- About right ......................... 2
- Depends on the situation .......... 3
- More .................................... 4
- Not coded .............................. 7
8. Among [his/her] family and friends, how many people are there who are immediately available to [him/her] whom [he/she] can talk with about anything, without having to watch what [he/she] says? [Pause, if no answer, prompt sequentially going one above ‘YES’.]

None .................................................. 1
1-2.................................................. 2
3-5.................................................. 3
6-10.................................................. 4
11-15............................................... 5
More than 15................................. 6
Not coded........................................ 7

9. Would [he/she] like to have more or less people like this? [Pause, if no answer, add] or is it about right for [him/her]?

Less ................................................... 1
About right...................................... 2
Depends on the situation.............. 3
More.................................................. 4
Not applicable ................................. 9
Not coded........................................ 7

10. With the one (those) [he/she] has, would [he/she] like to feel more free to be frank? [Pause, if no answer, add] or is it about right?

About right....................................... 1
Depends on the situation............ 2
More free......................................... 3
Not applicable ............................... 9
Not coded....................................... 7
11. Is there any particular person [he/she] feels [he/she] can lean on?

   No one .............................. 1
   Yes, but doesn't need anyone ...... 2
   Yes........................................... 3
   Not coded................................. 7

12. Would [he/she] like to be able to lean more or less on _________________?

   Less ........................................ 1
   About right............................... 2
   Depends on the situation............. 3
   More........................................ 4
   Not applicable .......................... 9
   Not coded................................ 7

13. Would [he/she] like to have someone else like this? [Pause, if no answer, add] or is he/she enough?

   Yes........................................... 1
   Don’t know ............................... 2
   Enough...................................... 3
   Not applicable .......................... 9
   Not coded ................................. 7

14. Does [he/she] feel there is one particular person who feels very close to [him/her]?

   No one ................................. 1
   Not sure ................................. 2
   Yes........................................... 3
   Not coded................................. 7
15. Would [he/she] like _____________ to feel closer, or not so close to [him/her], or is it about right the way it is?

- Closer ............................................ 1
- About right ...................................... 2
- Depends on the situation ................ 3
- Not so close ........................................ 4
- Not applicable .............................. 9
- Not coded ....................................... 7

16. Would [he/she] like to have more or fewer people like this? [Pause, if no answer, add] or is this about right?

- Fewer ............................................. 1
- About right ...................................... 2
- More ............................................... 3
- Not applicable .............................. 9
- Not coded ....................................... 7

17. When [he/she] is happy, is there any particular person [he/she] can share it with – someone who [he/she] feels sure will feel happy simply because [he/she] is?

- No one .............................................. 0
- Yes ............................................... 1
- Not coded ....................................... 7

18. Would [he/she] like to feel this more with _____________? [Pause, if no answer, add] or is it about right?

- About right ................................. 1
- More ............................................... 3
- Not applicable .............................. 9
- Not coded ....................................... 7
19. Would [he/she] like to have someone else like this? [Pause, if no answer, add]
or is this enough?

Yes ............................. 1
Don’t know ...................... 2
Enough .......................... 3
Not applicable ................. 9
Not coded ....................... 7

20. At present, does [he/she] have someone [he/she] can share [his/her] most private feelings with (confide in)?

No one .......................... 0
Yes ................................. 1
Not coded ........................ 7

21. Does [he/she] wish [he/she] could share more with ________________? [Pause, if no answer, add] or is it about right?

About right ........................ 1
Depends on the situation ...... 2
More ............................... 3
Not applicable ................... 9
Not coded ....................... 7

22. Would [he/she] like to have someone else like this as well? [Pause, if no answer, add] would [he/she] prefer not to use a confidant, [then add] or is it just about right for [him/her] the way it is?

Prefers no confidant .......... 1
About right ........................ 2
Depends on the situation ...... 3
Like someone else as well ...... 4
Not applicable ................... 9
Not coded ....................... 7
23. Are there ever times when [he/she] is comforted by being held in someone’s arms (hugged)?

No .................................................. 0
Yes.................................................... 1
Not coded......................................... 7

24. Is there anyone [he/she] would like to comfort [him/her] more in this way? [Pause, if no answer, add] or is it all right the way it is?

All right as is................................. 2
Yes.................................................... 1
Not applicable ............................. 9
Not coded......................................... 7

25. Does [he/she] think those at home really appreciate what [he/she] does for them?

Yes ............................................... 1
Not really ................................. 2
Depends on the situation ....... 3
Not at all ................................. 4
Not applicable ....................... 9
Not coded ......................... 7

26. Would [he/she] like any of them to show more appreciation?

Less ................................. 1
About right ............................. 2
Depends on the situation ....... 3
More ................................. 4
Not applicable ....................... 9
Not coded ......................... 7
27. Are there people around from whom [he/she] can easily ask small favours? Such as people [he/she] knows well enough to borrow tools, things for cooking or games.

No…………………………… 0

Yes—How many?       

Not coded ………………… 7

28. Would [he/she] like to have more or less of this? [Pause] or is it about right?

Less .............................. 1
About right ....................... 2
Depends on the situation ...... 3
More .............................. 4
Not coded ....................... 7

29. (Apart from those at home) are there people in (this town) to whom [he/she] can turn in times of difficulties? Someone [he/she] can see fairly easily who [he/she] could trust and whom [he/she] could expect real help from in times of trouble.

No…………………………… 0

Yes--How many?       

Not coded ………………… 7

30. Does [he/she] wish [he/she] had more of such help available? [Pause] or is it about right?

About right ....................... 1
Depends on the situation ...... 2
More .............................. 3
Not coded ....................... 7
General Questions

1. How long have you lived in <name of town>?

2. What do you do in <name of town>? Are you involved on any committees or in any organizations?

3. Tell me about <name of town>. What makes it special? Different from other places?

4. What are the main activities here (work and leisure)?

5. Do people work and play here or do they tend to leave <name of town> for work? for leisure and recreation?

6. What can you tell me about how people with intellectual disabilities are treated in your town? What services are available to them?

7. Do young adults with such disabilities work in <name of town>? Where do they work?

8. What do they do for fun?

Participation in the local community

1a. Do people here think of themselves as part of the local area?

1b. Do you know of individuals with intellectual disabilities who are part of the local area?

2a. Are people active members of local groups?

2b. Do you know of individuals with intellectual disabilities who are active members of local groups?

3a. Do people participate in voluntary or religious activities?
3b. Do you know of individuals with intellectual disabilities who participate in voluntary or religious activities?

**Reciprocity**

4a. Do people do and receive favours from others living nearby?

4b. Do you know of instances of people doing or receiving favours from someone with an intellectual disabilities living nearby?

5a. Do local people look after each other?

5b. Do local people look after individuals with intellectual disabilities?

6a. Who do people turn to for advice or to share good news?

6b. Who do people with intellectual disabilities turn to for advice or to share good news?

**Feelings of trust and safety**

7a. Do people feel safe in their own home? going out at night?

7b. Is the community safe for people with intellectual disabilities? Is it safe for them to go out at night?

8a. Do you know someone who has been a victim of a crime?

8b. Do you know of people with intellectual disabilities who have been victims of crime?

9a. Can people around here be trusted?

9b. Are individuals with intellectual disabilities trusted around here?

**Social connections**

10a. Do people chat with family, friends or neighbours regularly?

10b. Do people chat with others who have intellectual disabilities?
11a. Do people generally have close friends around here?

11b. Do individuals with intellectual disabilities seem to have close friend around here?

12a. Do people tend to go outside this area to visit their friends?

12b. Do individuals with intellectual disabilities tend to go outside this area to visit their friends?

**Citizen power**

13a. Do people formally complain about local services?

13b. Do you know of instances of individuals with intellectual disabilities formally complaining about local services?

14a. Have people in the community formed committees to fight local causes?

14b. Have individuals with intellectual disabilities joined committees to fight local causes? Formed committees?

**Community perception**

15a. Do people generally enjoy living here?

15b. Do individuals with intellectual disabilities generally enjoy living here? Do people ‘mind’ individuals with intellectual disabilities living here?

16a. Are there enough community facilities and public transportation?

16b. Are there enough community facilities and public transportation accessible to individuals with intellectual disabilities?
Sense of Community Scale (adapted from Nasar & Julian, 1995; participants will be asked to rate each items on a 5 point scale from “strongly disagree” to “strongly agree” and return the form anonymously)

1. I am quite similar to most people who live here.

2. If I feel like talking, I can generally find someone in this town to talk to right away.

3. I DON’T care whether this town does well.

4. The police in this town are generally friendly.

5. People here know they can get help from others in the town if they are in trouble.

6. My friends in this town are part of my everyday activities.

7. If I am upset about something personal, there is NO ONE in this town to whom I can turn.

8. I have NO friends in this town on whom I can depend.

9. If there were a serious problem in this town, the people here could get together to solve it.

10. If someone does something good in this town, that makes me feel good.

11. If I had an emergency, even people I do not know in this town would be willing to help.
Appendix G: Interview Guide for Other Community Members
**General Questions**

1. How long have you lived in <name of town>?

2. What do you do in <name of town>? Are you involved on any committees or in any organizations?

3. Tell me about <name of town>. What makes it special? Different from other places?

4. What are the main activities here (work and leisure)?

5. Do people work and play here or do they tend to leave <name of town> for work? for leisure and recreation?

6. What can you tell me about how people with intellectual disabilities are treated in your town? What services are available to them?

7. Do young adults with such disabilities work in <name of town>? Where do they work?

8. What do they do for fun?

**Participation in the local community**

1a. Do people here think of themselves as part of the local area?

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6b. Who do people with intellectual disabilities turn to for advice or to share good news?

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7a. Do people feel safe in their own home? going out at night?

7b. Is the community safe for people with intellectual disabilities? Is it safe for them to go out at night?

8a. Do you know someone who has been a victim of a crime?

8b. Do you know of people with intellectual disabilities who have been victims of crime?

9a. Can people around here be trusted?

9b. Are individuals with intellectual disabilities trusted around here?

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10a. Do people chat with family, friends or neighbours regularly?

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14b. Have individuals with intellectual disabilities joined committees to fight local causes? Formed committees?

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15b. Do individuals with intellectual disabilities generally enjoy living here? Do people ‘mind’ individuals with intellectual disabilities living here?

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16b. Are there enough community facilities and public transportation accessible to individuals with intellectual disabilities?
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2. If I feel like talking, I can generally find someone in this town to talk to right away.

3. I DON’T care whether this town does well.

4. The police in this town are generally friendly.

5. People here know they can get help from others in the town if they are in trouble.

6. My friends in this town are part of my everyday activities.

7. If I am upset about something personal, there is NO ONE in this town to whom I can turn.

8. I have NO friends in this town on whom I can depend.

9. If there were a serious problem in this town, the people here could get together to solve it.

10. If someone does something good in this town, that makes me feel good.

11. If I had an emergency, even people I do not know in this town would be willing to help.
Appendix H: Tables of Significant Statements and Formulated Meanings
Table H-1a: Significant Statements by Young Adults with Intellectual Disabilities in Town C

<table>
<thead>
<tr>
<th>Significant Statements</th>
<th>Formulated Meanings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “It’s not big. There isn’t that much traffic or anything.” ... <strong>What do you like about where you live?</strong> “It’s on a lake. It’s quiet.” <strong>Do you think people enjoy living here?</strong> “Yeah. Because it’s like probably a quiet town. And there’s lots of things to do.” <strong>Do you enjoy living here?</strong> “Yeah” <strong>Is there another place you’d rather live?</strong> “I’d rather live in a city because there’s more opportunities in there.” <strong>Do you think you might move to a city sometime?</strong> “Yeah, I plan on it.”</td>
<td>There is ambivalence about living in the town; it offers a peaceful quiet setting but there is a desire for more opportunities and social interaction.</td>
</tr>
<tr>
<td>2. “The lake, it’s peaceful.”</td>
<td>C_3</td>
</tr>
<tr>
<td>3. <strong>What do you like about where you live?</strong> “it’s peaceful and quiet.” <strong>What do you not like about where you live?</strong> “Just nobody to visit….It’s a pretty quiet town…just one quiet town…with nothing to do.” <strong>Do you think people enjoy living here?</strong> “No. Just a little hick town. Too quiet. It’s okay for the old, old guys like my dad and mom. But young people probably like chilling out in [the city] or something. I never made a change, but I want to leave.”</td>
<td>C_5</td>
</tr>
<tr>
<td>4. “kind of boring…stuck in the boonies.”</td>
<td>C_6</td>
</tr>
<tr>
<td>5. “It’s pretty boring…there’s not too many places to shop.”</td>
<td>C_1</td>
</tr>
<tr>
<td>6. <strong>Do you think people enjoy living here?</strong> “Yeah. It’s peaceful.” <strong>Do you enjoy living here?</strong> “No. I can’t wait to get away from this town….I wish I was still living in [the city]. I used to … and then I moved back here and I am stuck here again. Most of my friends live in [the city]. The ones I went to [high school] with….There’s not much to do. I call it the Ghost Town ‘cause it’s so boring.”</td>
<td>C_4</td>
</tr>
<tr>
<td>Significant Statements</td>
<td>Formulated Meanings</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1. “I have a couple [friends] and the rest are all far away…They moved, to [the city],…after they graduated.” C_1</td>
<td>There is a loss of contact with friends after high school; there is a sense of being left behind.</td>
</tr>
<tr>
<td>2. “But now all my friends are gone. ..they all moved out because they got jobs.” C_3</td>
<td></td>
</tr>
<tr>
<td>3. <em>How often do you spend time with your friends?</em> “Uh, not as much as usual. Not since school.” C_2</td>
<td></td>
</tr>
<tr>
<td>4. “I wish I was still living in [the city]. I used to … and then I moved back here and stuck here again. Most of my friends live in [the city]. The ones I went to [high school] with.” C_4</td>
<td></td>
</tr>
<tr>
<td>1. “I feel like I belong here. I got a lot of family that lives here. I’m related to pretty much all of [the town].” C_3</td>
<td>Extended family as contributing to sense of belonging in the community.</td>
</tr>
</tbody>
</table>
Table H-1a: Significant Statements by Young Adults with Intellectual Disabilities in Town C

<table>
<thead>
<tr>
<th>Significant Statements</th>
<th>Formulated Meanings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. “[most people] sit around the house and do housework, hoping they can get a job” …If tomorrow you had a chance to have any job you liked, what would this be? “Mechanic…Get to make nice things…cars and all that.” What do you think it would take to make this happen? “Not much…Get the machinery and all that…tools and everything.”</strong> C_6</td>
<td>There is a desire for paid employment but no concrete planning or preparation for employment.</td>
</tr>
<tr>
<td><strong>2. Have you thought of what type of work you’d like to do? “working with animals” Is there a place here where you could do that work? “probably not.” …Why do you want to work? “So I can move out of [this town] and to [the city].”</strong> C_1</td>
<td></td>
</tr>
<tr>
<td><strong>3. Would you like to have a job? “Someday, down the road.” Not necessarily right now? “No. Because my dad, he’s got [health problems] and I want to stay there for now until….See if he is going to be alright or not for awhile. If he ends up turning sick or something, then I’d be there.”</strong> C_3</td>
<td></td>
</tr>
<tr>
<td><strong>1. “There’s a lot of nice people in this community. And there’s a lot of people that can be ignorant with you. Like getting teased on the bus and stuff when going to school and stuff. That’s another reason why I quit going to school because I kept getting teased.”</strong> C_3</td>
<td>Teens</td>
</tr>
<tr>
<td>Significant Statements</td>
<td>Formulated Meanings</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1. “[My neighbour] helps me out, I help him out….It’s like working with a partner. Someone helps you, you help them back.” C_6</td>
<td>Reciprocity is natural for many.</td>
</tr>
<tr>
<td>2. “I just help people out now and again…just help them do lawns or something like that, carpenter work….I go up and help the old people up in [the next town] if they need a help. If they can’t reach the windows, I go up and wash the windows off for them…And there’s a lot of people that’s sick up around there that you have to do stuff for. Like, you know [name of woman], she used to work up at the public school in the [nearby hamlet]. And she’s not doing too well. We’ve been helping her.” … How do those volunteer jobs come about? Do people just approach you? Do you approach them? Is it organized? “I just go over and ask them if they want help with their car or skidoo or whatever they want to take off or something. Then they go ‘Alright’. I just do it by myself.” C_3</td>
<td></td>
</tr>
<tr>
<td>1. “[young people] just sit there and watch TV…hang out with my friend…I work a lot.” C_6</td>
<td>There are very few organized social and recreational activities for young adults.</td>
</tr>
<tr>
<td>2. “I phone a few of my friends and talk for a little bit and then do the dishes. That’s pretty much it…I watch movies…I play with the puppies and …and then I go outside for walks.” C_1</td>
<td></td>
</tr>
</tbody>
</table>
Table H-1b: Significant Statements by Caregivers and Family Members in Town C

<table>
<thead>
<tr>
<th>Significant Statements</th>
<th>Formulated Meanings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “I think boredom is a big thing sometimes...But I think in general, it’s not too bad. Umm, the reason I say that is that, uh, people do have a choice. I mean, if people want to move somewhere, then they’re free to move. We don’t keep them here. And if they did want to move to [this city] or [that city], then I would think that they would go. A lot of people have been here now for a long time, so they have those friends and they have those connections. So they see it as their home and this is where they want to be. Like everyone else who’s here, despite the complaints that nothing’s going on.” C_STAFF_1</td>
<td>There is a perception that if young adults with ID are staying it is by choice.</td>
</tr>
<tr>
<td>1. Re: sons with intellectual disabilities feeling part of the local area: “They stay to themselves. They’d rather do things on their own.” Re: participation in day programs: “They don’t like being with a bunch of people.” Re: volunteering: “They don’t want to leave the house.” C_FAMILY MEMBER_1</td>
<td>Social interactions are stressful for some.</td>
</tr>
<tr>
<td>1. “I think the population that we support here, because most of them are fairly high functioning, most of them don’t have a lot of very obvious, umm, disabilities or sort of, I guess, violent or socially unacceptable behaviours, you know, that are right out there. I think, uh, I think that makes a bit of a difference for the people trying to get involved.” C_STAFF_1</td>
<td>Community involvement is easier for those that are seen as similar.</td>
</tr>
</tbody>
</table>
Table H-1c: Significant Statements by Other Community Members in Town C

<table>
<thead>
<tr>
<th>Significant Statements</th>
<th>Formulated Meanings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “My sense is that we just accept them because we tend to see them every day, especially those that are working with [the agency]. They have the drop-in centre. They have a hot lunch, I think it’s once a month. So there’s a number that I’m used to seeing. My children are used to seeing them. They know them. They talk to them.” C_COMMUNITY MEMBER_1</td>
<td>Being seen leads to being recognized and accepted.</td>
</tr>
<tr>
<td>2. “I really believe they’re better off certainly socially (living in this town); they’re not ghetto-ized or ignored.” C_COMMUNITY MEMBER_2</td>
<td></td>
</tr>
<tr>
<td>3. “I think they’re quite accepted and I think part of it is that they’re visible. That’s something that struck me right away is the visibility. I think because of the proximity of, especially, the location of [agency] office. So the clientele is right out in the urban core—whatever urban core we have— they’re right here. So they’re very highly visible. And I think in like of that, the general population, you know, is quite accepting and warm and, from what I’ve seen, you know, very accommodating to maybe some of their special unique characters and things like that.” C_COMMUNITY MEMBER_3</td>
<td></td>
</tr>
<tr>
<td>4. “I was very pleased to see the high visibility of those people (with intellectual disabilities) within the community, and to see them I feel, treated quite well and accepted and cared for. And, you know, out and about socially. Whereas in larger communities, at times you’d be hard pressed to bump into anybody with an intellectual disability for weeks at a time. And therefore some people would feel uncomfortable, make strange, because they don’t have the exposure.” C_COMMUNITY MEMBER_3</td>
<td></td>
</tr>
<tr>
<td>5. “They’re certainly welcome in this home. And they do come in and out of here. I can speak for [my husband]</td>
<td></td>
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Table H-1c: Significant Statements by Other Community Members in Town C

<table>
<thead>
<tr>
<th>Significant Statements</th>
<th>Formulated Meanings</th>
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<tbody>
<tr>
<td>and I. We have no prejudices whatsoever when it comes to them. And some of them, my kids are even getting to know them. ‘How’s so and so?’ and ‘What’s he doing?’ and ‘Is he coming for dinner tonight too?’” (husband adds) “But I don’t think we’re special though. I think that the community generally is very good with them. There’s a few that are really, they’re an important part of the community.” C_COMMUNITY MEMBER_4&amp;5</td>
<td></td>
</tr>
<tr>
<td>6. “There’s a fair number (of persons with ID) relative to the population. There’s a, I mean there’s a real familiarity with…There’s no, not, no real marginalization because, you know, the social gathering place will be the store. People go to the store once or twice, you know, two of three times a week. And there’s people like [Larry] and everyone knows… Everyone knows everyone’s business so it’s…I think it’s good that way, you know? I think there’s a …I don’t think people with intellectual disabilities are seen as a threat to anyone. I don’t think there’s any, there’s no real resistance to them.” C_COMMUNITY MEMBER_2</td>
<td></td>
</tr>
<tr>
<td>7. “I can think of half a dozen (people with ID- men) that will stop to tell me what good things or bad things are happening in their lives.” C_COMMUNITY MEMBER_2</td>
<td></td>
</tr>
<tr>
<td>8. “There’s a gentleman, [Paul], comes and does the shoveling and clears off the walkways. And I see him walking daily. We have another fellow who, in the summer, we see him with his fishing pole, and he walks around. There’s another gentleman that I’ve known over the years, and, yeah, I love to see him at all the annual general meetings for all the organizations, and this and that. You know, they’ve been out and about, and I’ve come to recognize them.” C_COMMUNITY MEMBER_1</td>
<td></td>
</tr>
<tr>
<td>1. Do you know of individuals with intellectual disabilities who become part of local groups? “…he ran the coffee Gender</td>
<td></td>
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Table H-1c: Significant Statements by Other Community Members in Town C

<table>
<thead>
<tr>
<th>Significant Statements</th>
<th>Formulated Meanings</th>
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<tbody>
<tr>
<td>campaign here for the Legion…he’s a member of the Legion…he’s served on committees…[name of a man with an intellectual disability], he gets up there every Tuesday when the paper comes in to help unload the truck…[name of a third man with an intellectual disability], he was doing Meals on Wheels.”</td>
<td>differences are noted.</td>
</tr>
<tr>
<td><em>What about women with intellectual disabilities in the community?</em> “We do have a few ladies, but not like there are men. And the ladies tend to live with other ladies and seem to survive a little better than the men. They’re not needy. I don’t mean that in a negative sense. But, umm when the fellas are feeling down and out, they have to get to a family to feel good. When the females are feeling down and out, they sit and talk to each other.”</td>
<td></td>
</tr>
<tr>
<td>C_COMMUNITY MEMBER_4&amp;5.</td>
<td></td>
</tr>
<tr>
<td>2. “There’s [name of man with ID including last name]. He cuts lawns and shovels. You must have seen him around. He does a lot of that…[name of a second man with ID including last name] works here sometimes, helps out with our paper deliveries. And [name of a third man with ID], I don’t know his last name. He moved to [name of another town]. He lived here all his life…he did quite a bit of work around. And then there’s [name of a fourth man with ID] who does the paper shredding….<em>Where are the women?</em> “The men are in the community. Well, they’re in the streets. And these guys are all kinda, they hang around. They seek the community. They want to know everyone….which makes them more visible than anyone because they have time. And they sit in front of the store and wait for people to talk to. Because they’re looking for community. They have a real need for that… I think the women are more on their own. Maybe they’ve had, maybe they’ve been, uh, taken advantage of.”</td>
<td></td>
</tr>
<tr>
<td>C_COMMUNITY MEMBER_6.</td>
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<th>Table H-1c: Significant Statements by Other Community Members in Town C</th>
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<td><strong>Significant Statements</strong></td>
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<tr>
<td>1. “THEY (people with ID) like to chat. And so, and some of the barriers are broken down by that. The rest of us might be a little bit more reticent when we talk to each other. But whenever I meet one of them, ‘Hi [Joyce], how are you?’ – bold, loud.” C_COMMUNITY MEMBER_7</td>
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<td>1. “There is another gentleman who spends his days either mowing lawns or shoveling snow or sweeping parking lots. And he gets paid for that. But he works very very VERY very hard, and he’s well known throughout the community. And that’s what people employ him as, he’s dependable for that.” C_COMMUNITY MEMBER_7</td>
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<td>2. Re: employment “I can’t say that I’ve seen them in any stores. Certainly doing lawn maintenance. There’s the [town] lawn service and that sort of thing…I think the opportunities are really limited, because they’re competing with adults who are fully capable and who are having difficulty finding work. So I think it’s very difficult for them to find employment. It’s difficult for anyone to find employment in this area.” C_COMMUNITY MEMBER_1</td>
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<td>3. “We have another fellow who is involved with [the agency]. We hire to do certain shredding (confidential). It’s wonderful – he can’t read. So he sits here and he shreds papers and crushes cans and that’s what he does to keep busy.” C_COMMUNITY MEMBER_1</td>
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<td>Significant Statements</td>
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<td><strong>4. “There’s an attempt to accommodate. I could think of two or three that have held kind of protected type jobs, you know, around the grocery store, gathering up carts outside and shoveling the store, putting salt down on the ice. That kind of thing. And I think, again, because of it’s a small community, everybody knows everybody. Everybody knows what everybody’s limitations are and what people’s capabilities are too.”</strong> C_COMMUNITY MEMBER_1</td>
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<tr>
<td>Employers, and the community in general, are supportive of those who want and can work.</td>
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<td><strong>5. “We have a gentleman in the community who’s started his own business, recycling. So he gathers recycled paper, and tins, and bottles, and does that. He’s fairly challenged. His mother supports him through that. And all of us in the organizations, when we can, we save our garbage for him to be able to help support him that way.”</strong> C_COMMUNITY MEMBER_7</td>
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<td><strong>6. “So some people have managed to get a niche that they can work in, and satisfy, and certainly the community is willing to support them as they can.”</strong> C_COMMUNITY MEMBER_7</td>
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<td><strong>7. Are there jobs for them (adults with ID)?</strong> “Not many. But there’s not many jobs for a lot of the people even without disabilities….we’re not well endowed with jobs. It’s a challenge for everyone…they’re busy (with agency) but not necessarily employed.” C_COMMUNITY MEMBER_3</td>
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8. “Some of them do volunteer work. We have a gentleman, for instance, who – so he can still visit us – every week, he does our garbage for us. Every week he goes around and empties all of the garbage pails and puts them into the bin. And he gets coffee or pop. And he gets invited to any special events that we have, etc. And that is a minor service for us. But it makes him feel valued….Everybody wants to feel useful to their community, and I don’t think just because you have intellectual disabilities, that changes. So they want to feel needed and important and valued. And so doing even volunteer work or things like that, it might not be much to some of us, but to them it’s important. It makes them feel important. Like all of us. I mean, you and I do the same: we want to feel like we’re doing something worthwhile in our life, and not just wasting time.”

C_COMMUNITY MEMBER_7

1. “They (young adults with intellectual disabilities) have a close group amongst themselves. The [agency] supports and helps. They go for out-trips and things like that.” C_COMMUNITY MEMBER_7

2. “They know people and people are nice to them. But I don’t think they build BEST friends outside the disabled community. Don’t know if that’s good or bad, but that’s the way I perceive it. The other people work with them so they know them and are friendly and would help them. But I don’t think they’d be best friends.”

C_COMMUNITY MEMBER_7

3. “There isn’t a lot of recreational activities…social type of recreational activities, ball teams, things like that; I don’t think that I have ever seen any of the intellectually disabled part of those events. So, in that way, I don’t

Social segregation occurs. Agencies may play a part in it.
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<td>I can’t say that the youth of the community are supportive of the disabled youth. I can say that the adults of the community are supportive of the adult disabled, but I can’t say the same thing about the youth. I’ve seen some, a lot of preying on them, because some of the disabled youth get monies, pensions…And the others, some of teens/youth not seen as</td>
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Table H-1c: Significant Statements by Other Community Members in Town C

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<td>the young people will use them, and they don’t have the intellectual ability to make that judgment that those aren’t the safe group for them to run with. So we end up with some, sometimes drug issues or really being preyed upon. Taking their money and using it for things, for their own purposes. It’s sad and we try… But I really, I really feel badly for disabled youth.” C_COMMUNITY MEMBER_7</td>
<td>supportive</td>
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<td>1. <em>Re: Transportation:</em> “You have to be a little bit more self-reliant in the area…you have to have contacts. And I suppose that’s what makes it a closer-knit community, because we know that those resources aren’t available, so you have to try and help others. And people do volunteer to do the driving and try and look out for neighbours.” C_COMMUNITY MEMBER_1</td>
<td>Transportation is a major issue but solutions are being put in place.</td>
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<td>2. There’s no public transportation. There’s a fledgling transportation program being developed.” C_COMMUNITY MEMBER_6</td>
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Table H-2a: Significant Statements by Young Adults with Intellectual Disabilities and Their Mothers in Town B

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<td>1. (mother) “People are extremely wonderful with you (mother says to son), aren’t they? Everybody knows (name of son)! And there isn’t a single person who wouldn’t go by and give him a high five.” (son adds) “Or a hug.” (mother resumes) “Yeah, he gets lots of hugs, you betcha! For [name of son], it’s really a wonderful community, an accepting community for him.” … “I’m not sure that they (other persons with ID) have the integrated acceptance that [son’s name] has. [Son’s name] is extremely integrated. Goes to all the local hockey games and everybody includes him in their activities. He has more inclusion than some of the others who have more social life with just each other. But [son’s name] has broken through those boundaries almost. He’s very social. He loves to talk. He’s quite open and honest. I always pushed for inclusion. I always told him he could do things.” … “I feel extremely, myself - as a mother of a challenged adult, I feel personally extremely grateful that he has the acceptance in the community that he does. Because I have seen examples of it not working so well … I am extremely grateful that [name of son] is as well accepted in this community as he is.” B_WITH FAMILY MEMBER_3 (highly social young man with a visible disability whose family is very involved in the community)</td>
<td>Being seen, known, accepted and included vary. These are enhanced by the family’s prominence in the community, the social skills of the young adult with an intellectual disability and his/her parents, and the visibility of the disability.</td>
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<td>2. (mother) “The special needs are part of the community. And you see them on the street, walking the streets. And people here know them, and, you know, they’re part of the everyday community here. That part’s part of something that I like here. But it’s not any different from [name of small town] where we came from.” … “I see them walking down the streets and most of them know all the individuals by name, especially the storekeepers and things.” … “There are people in the community who will interact with them (persons with</td>
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Table H-2a: Significant Statements by Young Adults with Intellectual Disabilities and Their Mothers in Town B

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<td><em>ID</em>)….because a lot of people are related, they’re like somebody’s grandchild or somebody’s great-niece, or somebody’s…you know…everybody’s connected to somebody. I think that helps a lot.” B_FAMILY MEMBER_3 (young man with severe multiple disabilities whose family has a long history in the community and whose mother is very social)</td>
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<td>3. <em>(mother)</em> “Just from our personal experience, I don’t think there’s enough understanding, awareness of people with disabilities. I think just due to lack of exposure…I know even trying to find [daughter’s name] a co-op in high school.” <em>(daughter adds)</em> “That was quite the challenge.” <em>(mother resumes)</em> “We found at the time…not very many employers who were really open to having someone with a disability doing a co-op or with possible future employment. It was very limited; I was sort of surprised being a smaller community….We don’t find them that willing to include.” B_WITH FAMILY MEMBER_2 (young woman with a less visible disability whose family recently moved to the town from a larger center and who describes herself and her family as ‘homebodies’)</td>
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| 1. *Re: leaving school*(mother) “At first, he found that it was extremely difficult. He had bonded with so many of the students. … He had a really hard time trying to figure out what to do with his whole day when he didn’t get up and have to go to school. It was a whole social issue there. There was no contact with other kids on a regular basis. Everybody at the [agency] was a tad older. So he didn’t really have as many peer times, you know, for social or projects or trips or different things….After a while, that worked out alright. But I had to try to make him realize that ‘You are no longer in school. You have to move on to other kinds

Transition from school meant loss of connectedness as well as day
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<td>of activities for your day.’ …It was hard for him to make the transition.” B_WITH FAMILY MEMBER_3</td>
<td>activities.</td>
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<td>2. <em>(mother)</em> “I found a lot of assistance while she was a student for certain things. But once she finished school, it’s like we don’t exist anymore. At least that’s the way I feel.” B_WITH FAMILY MEMBER_2</td>
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<td>1. <em>(mother)</em> “I know that we have some really incredible special needs people that come to this center <em>(agency).</em> There’s a few of them that just absolutely, well, they all have a little piece of my heart, so…But there’s a couple of them that are special to me. And I’ve only met them since I’ve come here. They all know [son’s name], and if I’m downtown shopping, they come up to me and talk to me. And say hello to [son’s name]. It’s just kind of nice.” B_FAMILY MEMBER_3</td>
<td>The agency fosters a sense of community for those it supports.</td>
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<td>1. <strong>What are you doing now instead of going to school?</strong>  “I’m working with *[name of the agency]. Are you here every day? “Other than Wednesday, I am only here at night on Wednesdays.” <strong>What do you do here on Wednesdays?</strong> “I clean.” <strong>And the rest of the time, when you come, what do you do?</strong> “I do the mail run for them and then I also do cleaning every day, but Wednesdays is the later one.” <strong>What time do you come in?</strong> “one o’clock” <strong>How long do you stay when you come to do the mail run?</strong> “It’s usually between half an hour to an hour.” <strong>And the cleaning, how long does that take?</strong> “Tuesdays and Thursdays it only takes half an hour…Monday, Wednesday, Friday, it takes two hours.” <strong>Do you do that alone or with someone else?</strong> “I do it by myself.” <strong>What do you do in the mornings?</strong> “Nothing.” <strong>And the rest of the afternoon, when you come here, do you have other things that you do after?</strong> “Monday and Wednesdays after the mail run, I used to go to</td>
<td>Many adults with intellectual disabilities are reliant on the agency to provide a patchwork of day activities; others feel</td>
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### Significant Statements by Young Adults with Intellectual Disabilities and Their Mothers in Town B

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<td>[hamlet] and go to fitness.” What do you do on week-ends? “Nothing.” B_5</td>
<td>unsupported or wishing the agency could do more</td>
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<td>2. Re: relationship with someone outside his immediate family (mother) “The programs that are in place are good, but they’re spread too thin….That’s what happened to [son’s name]. Like, there have been at least four people sort of have him on their agenda and they will work with him for a time. But they realize too, like he’s not so challenged….and they don’t have the time.” B_WITH FAMILY MEMBER_3</td>
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<td>3. Re: case management (mother) “There’s nothing in our situation. I really feel like I’m sort of left on my own. Re: respite care and other residential supports “That’s apparently there, but we’re responsible as guardians or parents to arrange that on our own. And being new in a community…And to the extent that I would like to know people to put, you know, to have in charge in that way…That’s been very difficult. It tried it once, and did not have a good experience, so I just don’t go there. We provide as a family and that’s it.” B_WITH FAMILY MEMBER_2</td>
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<td><strong>1.</strong> <em>(mother)</em> “This center <em>(referring to the agency)</em> tries to do things for them, like get out. They do day trips and different things certain times of the year. Umm, [son’s name] sometimes can manage some of them, but a lot of them, he doesn’t really qualify, because his needs are too high. So he’s gone to the odd dance, but not a lot. Umm, because he would have to be pushed around in a wheelchair to go shopping.” B_FAMILY MEMBER_3</td>
<td>Social activities, even those organized by the agency, are not for everyone.</td>
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<td><strong>2.</strong> “It would be nice to have people my own age to hang out with. And to have fun with.” <em>(mother adds)</em> “The one thing [name of daughter] has found is a lot of things that are provided, which is basically through [name of the agency], she’s higher functioning. So it’s just not a fit.” B_WITH FAMILY MEMBER_2</td>
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<td><strong>1.</strong> “I do have friends who live far away, but I don’t go see them. I talk to them...phone or internet.” … <em>Re: siblings</em> “I don’t see them often because they’re working. But I talk to them on msn.” B_5</td>
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<td><strong>2.</strong> <em>Re: friends who live outside the area</em> “Well, I’ve visited them, but I’ve met them on the internet.” …”I met this one guy face to face who’s been on the youth exchange one year and then I met his friend on the internet, on msn.” B_1</td>
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<td><strong>1.</strong> <em>(mother)</em> “I think most of what they do is volunteer….Like I said, there’s not even a lot of work for even the regular person, let alone a special needs person.” B_FAMILY MEMBER_3</td>
<td>Paid employment opportunities are scarce for</td>
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| **2.** *Why aren’t you still working at [agency-sponsored job]*? “Because it’s just seasonal.” *Do you think you’ll work there again in the summer*? “No. Because they only hire so many people every year. And then if you
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<td>worked there the year before, then you don’t get the job.” B_1</td>
<td>all.</td>
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<td>(mother) “As to earning real income, there are placements available but nothing seems to really be where they could earn their own keep.” B_WITH FAMILY MEMBER_3</td>
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<td><strong>1.</strong> Do you think it is important for people to work? “Yes”. Why? “Because it makes you happy. And you’re not sitting at home and doing nothing. And you’re not bored and depressed like me some days. It’s really hard. Plus you get to have the experience of working with others, of getting into relationships with your peers at work.” B_WITH FAMILY MEMBER_2</td>
<td>The social benefits of employment are recognized.</td>
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<td><strong>1.</strong> What would be your perfect job? “typing on the computer”. What do you think it would take to make this happen? “Do my resume.” Do you have one? “I used to, but I don’t know where I put them all.” B_5</td>
<td>Employment is seen as something that comes along rather than something adults should plan for.</td>
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<td><strong>2.</strong> “Someday, I want to go to school and get my early childhood education.” When do you think that will be? “I am not sure.” Are you working on that? “Kind of; it’s just something in my head.” B_1</td>
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<td><strong>3.</strong> (mother) “I always said that [son’s name] could be the perfect Walmart greeter. And there is the potential of a Walmart coming here, and he wants that job badly. So if something came along, he would be able to work full-time and support himself.” B_WITH FAMILY MEMBER_3</td>
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<td><strong>1. Do you have a job?</strong> “Actually, no, because of transportation issues.” Do you live in town or outside of town? “We’re about six kilometers south. I was offered a job at [name of store]. It cost $25 round-trip for people with disabilities, $25! A taxi from where I live? $20 they were going to charge me every day. So then I’d be working for peanuts. I’d like to make a little bit too, because I’ve worked hard for that.” (mother later explained) “Even with getting her into work without us having to drive her. … It’s an on-call basis, to start off with, you know, which hopefully would work into something more scheduled. That’s not really something we felt was fair for us…For her to have to use the transit for the disabled, $25 round trip. So we sat down and worked it out with what she’s allowed to earn extra over and above her pension. It would end up costing her money.” B_WITH FAMILY MEMBER_2</td>
<td>The cost of getting to work can be a barrier to employment.</td>
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<td><strong>1. Why do you live at home?</strong> “To be close to my family.” (mother adds) “He actually wants his own apartment, to live somewhere else. But he doesn’t make enough money, really to afford a $600 a month apartment. His pension is $700. So right now, there isn’t really anything he could afford. “…We bought a house in town with a basement apartment, a potential basement apartment sort of started in there. We had our father-in-law living there. [name of son] is supposed to move in in the spring.” …”I realized that the housing situation in this particular community was very grave. There wasn’t any opportunities for even a challenged person or a senior or a single or anything; we’re very limited with housing.” B_WITH FAMILY MEMBER_3</td>
<td>Affordable housing is limited but some parents are finding solutions.</td>
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<td><strong>2. Why do you live at home?</strong> “Because of the cost….And I get along good with my parents. We’re very similar, so we don’t really have a problem. That’s basically it. I’m happy there.” (mother adds) “We</td>
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<td>purchased that house basically because of the way that the lower level was. We thought that would be good for [daughter’s name]. It’s a walk-out level that she can basically have the run of, other than she’d have to share the kitchen and laundry facilities. “ B_WITH FAMILY MEMBER_2</td>
<td>There are civic engagement opportunities for young adults with intellectual disabilities.</td>
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<td>1. <em>(Mother about her son’s involvement in advocacy)</em> “His focus is more like for the challenged folks and for the things that they have to cope with. So those are more his advocacy focuses. But yes, he will participate in, you know, election committees. And he was part of a rally there for them. Or he will participate in church functions. He likes to go to church every Sunday. And if they have their fundraising or doing something like collecting for groups and donations.” <em>(son adds)</em> ”we are in the parade as well.” B_WITH FAMILY MEMBER_3</td>
<td>The invisibility of the disability can lead to insufficient assistance which is felt as discrimination.</td>
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<td>1. “It depends on the person. Like sometimes they treat you bad. But there’s other people that treat you nice. So it just depends on who you get, type thing. If you’re going to go out to a store, for example, I can’t read, for example…If I’m looking for a Céline Dion cd or something, and I ask someone, ‘Oh, can you help me find the Celine Dion cd?’ Well, some people will be nice enough to go and help you pick out the cd. But there’ll be others, ‘Oh, they’re just right over there’. And I can’t read the cds, so it’s quite complicated sometimes.” B_WITH FAMILY MEMBER_2</td>
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<td>2. <em>(mother)</em> “Even with school, she was always in the catch twenty-two. She didn’t fit here, and she didn’t fit here, and it’s been very difficult.” <em>(daughter adds)</em> “It’s been like that for my whole life.” <em>(mother resumes)</em></td>
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<td>“Yeah, and it’s a very invisible disability, which sometimes is a positive, but not always.” B_WITH FAMILY MEMBER_2</td>
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<td>1. <em>(mother)</em> “Coming from the city, I used to have terrors thinking that young people would give him drugs or hurt him or want to fight with him because he was a little gullible. You know, try and get him in trouble?”…”He’s extremely lucky to be in a community where a lot of the time things are safe and there isn’t the same kind of gangster psychology behind the groups of kids like there is in the city.”B_WITH FAMILY MEMBER_3</td>
<td>Contrasts with larger centers are both positive (safety) and negative (opportunities for social and educational pursuits).</td>
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<td>2. <em>Re: having moved to the town from a larger center (mother)</em> “The part that I find hard as a parent is having two children with special needs. Sometimes I question whether I made the right decision for them. I know they’re happy in (name of town) because of nature….They enjoy a lot that’s here, but socially-wise and our school system, compared to what they would have had available to them in a city, it’s greatly lacking.” B_WITH FAMILY MEMBER_2</td>
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<td>1. “They (individuals with intellectual disabilities)’re all known, you know, and most of them by name, umm, which is fine. It’s great, actually.” B_COMMUNITY MEMBER_4</td>
<td>Being known and knowing others.</td>
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<td>2. Re: safety for individuals with intellectual disabilities “I’ll certainly see them walking in town at night. And, interestingly enough, most of us know who they are, and they many know who we are. And, yeah, there’s a bit more security her than I, say, downtown Toronto.” B_COMMUNITY MEMBER_7</td>
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<td>3. Do local people look out for individuals with intellectual disabilities?”I would say they do…Because I know we have had reports where, you know, someone has seen someone hitchhiking or they know them and, ‘Oh, I saw so-and-so and I saw them walking’ or doing whatever. And it’s noticeable and they’re more noticeable in the community because it is so small….I know even one night we (police) saw a young adult walking along the street. We knew there was something wrong and there was obviously a problem. And we’re more apt to stop and talk to them too because it’s you know, not what you’d normally see.” B_COMMUNITY MEMBER_5</td>
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<td>4. Do local people look out for individuals with intellectual disabilities? “People ask if they need anything, if they are in distress. I think [name of town] is great for that.” B_COMMUNITY MEMBER_1</td>
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<td>5. “My son plays for the Junior A. Folks with intellectual disabilities are so thrilled to be able to say they know him and get his autograph.” B_COMMUNITY MEMBER_1</td>
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<td>6. “I happen to know them just because, I guess just because its’ important to me to know those people, you</td>
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<td>know – to be able to speak to them. And to experience the pleasure when they can remember who I am, and answer me back – which is a delight with some of the kids, you know?” B_COMMUNITY MEMBER_3</td>
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<tr>
<td>7. “But it (persons with intellectual disabilities being included)’s more so since they’ve had their apartments here and had blended. Whereas before, we weren’t exposed to as many, so we didn’t have that blessing of knowing who they are and growing with them, and having them teach us.” B_COMMUNITY MEMBER_8</td>
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<tr>
<td>1. Do you know of individuals with intellectual disabilities who are active members of local groups? “One is a volunteer for the Terry Fox Run. She goes to meeting and all.” B_COMMUNITY MEMBER_1</td>
<td>Opportunities for Civic Engagement but some Symbolic participation</td>
</tr>
<tr>
<td>2. Do you know of individuals with intellectual disabilities who participate in religious activities? “[Jennifer] goes faithfully (to church). She is involved in the Shoe Box Charity. [Melissa] goes to church every Sunday. They share their stories with me; that’s how I know.” B_COMMUNITY MEMBER_1</td>
<td></td>
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<tr>
<td>3. Do you know of individuals with intellectual disabilities who are part of the local area? “Yes, a lot of them get this through volunteering. [Duncan] goes to the Fire Department and has coffee with the men there. They even gave him a jacket. He is part of it.” B_COMMUNITY MEMBER_1</td>
<td></td>
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<tr>
<td>1. How would you say they (individuals with intellectual disabilities) ’re treated by the community? “I think they are, umm, they’re well-served by the community, okay? But sometimes I get a feeling that they’re a bit invisible to the community, that they’re just there. You always see them walking down the street, you always see them doing this or that. You see them, and that the community doesn’t stop and say hello. But</td>
<td>Tolerated but not seen/lack of engagement</td>
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Table H-2b: Significant Statements by Community Members in Town B

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<td>it’s tolerant. It’s accepting. There are no problems but it’s just as if maybe they’re a little bit invisible, you know? Which bothers me; I don’t like to see that, you know? I mean they all have names, you know, it doesn’t hurt you to say, ‘Hello [Wendy], hi [Daniel], hi [Drew], hi [Liam].’” B_COMMUNITY MEMBER_3</td>
<td>Divergent perceptions of the town re: inclusion</td>
</tr>
<tr>
<td>1. “We, the community needs to become more involved with people with intellectual disabilities. There’s no question about that.” B_COMMUNITY MEMBER_3</td>
<td>Lack of awareness of how to engage with persons with intellectual disabilities</td>
</tr>
<tr>
<td>2. Tell me about [name of town]? What makes it special, different from other places? “I think the nice thing about our community is the care for the special needs. And that they are included in the community. And that everyone looks out for them. And I think that’s a beautiful thing about our community.” B_COMMUNITY MEMBER_2</td>
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<tr>
<td>1. “But most of the people in the community haven’t got the slightest idea of how, and the answer would be, well, get on the board of [name of agency]. That’s not really where a lot of people want to be, you know? I mean, it would be so simple to do things to bring the two groups together. Not that they’re disparate, it’s just they’re invisible, you know? They ARE invisible.” B_COMMUNITY MEMBER_3</td>
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| 1. As far as recreation goes, do they take part in what you consider the same sort of activities in an integrated Agency as


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<td>way with other residents? “No, no I don’t see that. I see them very much having their own programs that are more programs which are organized for them. If I could ever make a suggestion to the [name of agency], it would be – open those programs and invite the community in. Then, maybe you could go the other way also. On the other hand, I noticed recently at an all candidates night, that two of the clients (adults with intellectual disabilities) were there….Often at an artistic performance, particularly at a musical performance, you’ll see one or two that love music are there. But not generally speaking.”</td>
<td>hindering social inclusion</td>
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<tr>
<td>B_COMMUNITY MEMBER_3</td>
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<td>2. “As long as you have an organization like [name of agency], which in some cases is between the public and their clients, the public really doesn’t know (what individuals need, how to help). And I’m not saying [name of agency]...it’s a very difficult place to be in, it’s a difficult thing to comment on. But as long as you buffer, then how is the community supposed to know that there is a need? Because the need is always expressed in terms of [name of agency]: ‘We need members, we need money, we need whatever.’ Not ‘[Jim] needs…’ but ‘[name of agency] needs’. There’s no appreciating or knowing what those people need, unless you, on an individual basis, and you’re at a restaurant and young [Rosanna] who walks with a walker is having trouble going through the doo, you help. But you have no concept of what [Rosanna]’s other needs might be.” B_COMMUNITY MEMBER_3</td>
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<tr>
<td>1. Are there enough community facilities, transportation, services in [name of town]? “If they can afford them, yes. Even the [name of town] transit, and we have Community Care that both have transportation facilities available but</td>
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<td>but there is a cost to both of them so if cost isn’t prohibitive. I mean the cost of the service certainly seems reasonable to me but if you are living on ODSP that extra $15/month to $25/month that you might need to do something. So if it is not covered under the need for a doctor’s appointment or something like that, then it would, I think would be cost prohibitive but they are in place, they are here so if the cost can be looked after, they are both excellent services both of them.” B_COMMUNITY MEMBER_6</td>
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<tr>
<td>2. “Ontario Works will pay for transportation to the gym but ODSP will not cover it. There is this one girl (young woman with an intellectual disability) who can no longer come because of this and she has so much to give. [Name of president of the club] looked into it but nothing could be done.” B_COMMUNITY MEMBER_1</td>
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<td>3. “Transportation is the biggest issue. They are involved in SO much. They do more than my kids do. Their lives are very fulfilled. If they are not involved with [name of agency] they don’t get these things (activities and transportation). One woman moved out of town because she could not afford rent. Now she can’t get to things because of transportation.” B_COMMUNITY MEMBER_1</td>
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<td>4. <em>Re: transportation for persons with intellectual disabilities</em> “I believe they [agency staff] have their own vehicles. And part of their job is the transportation of the people involved in that group. So, I mean, they do have a way to get from Point A to Point B, and there is a way to get there. And like I said, I’ve seen them out to community functions and doing things, and there is a worker with them, and they’ve been transported</td>
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<td>“The majority (of individuals with ID) don’t have family here. They go visit parents at Christmas and Thanksgiving. We have such a good program here (referring agency) so it is an attraction. I would rather have my child be in a group home here because they are so accepted by the community.” B_COMMUNITY MEMBER_1</td>
<td>In-migration</td>
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<td>“Many of these young people (with intellectual disabilities) are not from here. They arrived and because of the local [agency]. It’s a business, and that’s there business, and so they need the clients to get the grants to run the organization…So they have taken enough people into the community to justify what’s going on. And they do a good job, they do a good job. But as far as introducing those people to the community, as far as doing that OUT there to the community, no that doesn’t happen.” B_COMMUNITY MEMBER_3</td>
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<td>“I’m actually trying to think if there are any (young adults with ID) local, locally born, right at the moment. I don’t think so. So many of them have lived here for so long, that – and don’t forget that some of them came from institutions – umm, so there isn’t another place that’s home, you know?” B_COMMUNITY MEMBER_3</td>
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<tr>
<td>Do people mind individuals with ID here? “No, I can’t image. I can’t think of anyone who would mind that. I mean, it’s a little industry actually. Maybe one shouldn’t say that, but it is a little industry. So there is a financial benefit to the community.” B_COMMUNITY MEMBER_3</td>
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<td>5. <em>RE: individuals with ID who were not originally from the town</em> “I think we were happy to see them come, just because we know it is a smaller community and we are accountable to everyone. Everyone knows everything. And so, we have, or at least I have a sense that it’s safer for them here. And the connection is that there are people that are going to be looking out for them. I marvel. I’d like to see how they do it in a larger center.” B_COMMUNITY MEMBER_2</td>
<td>Stereotype, prejudice, discrimination</td>
</tr>
<tr>
<td>1. <em>Re: town’s expectations of persons with ID</em> “Somebody would say ‘Look at the way that person’s behaving! I don’t like the way that person’s behaving!’ Now there could be two responses. One would be, ‘Yeah, that’s really disgusting, he should stop.’ The other response is, ‘Oh, lighten up. He’s a client of [agency].’ Okay? I’ve heard that, you know? Or, ‘I really disapprove of what that person’s doing.’ ‘Umm, well, he’s a client of [agency] so leave him alone!’ I have been known to call [name of agency] and say ‘Hey, there’s a little problem. If you came downtown, maybe one of the guys should come down and see if you can…’ Because, you know, in addition to intellectual problems, we also have many cases of emotional problems, and so it’s a different scale. If an empowered person or two stand in the middle of the street and shout at the cars, the cops would be called. If a disabled person does it, he’s part of [agency], let’s just get him on back there. So, no, it’s a different scale. I’m not saying that’s valid, I’m just saying it is.” B_COMMUNITY MEMBER_3</td>
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<td>2. <em>RE: opportunities for employment for your adults with ID</em> “I’ve see them…a few…‘I’ve see them many times in restaurants. And I’m not convinced that’s the place. And I say this not critically but many times we</td>
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### Table H-2b: Significant Statements by Community Members in Town B

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<td>rush and rush and rush. And we have to have more teaching and understanding about them, I think, if they’re to be working in restaurants and things….Candy stripers yes, or helping. And like [Liam] does, at the door. You know, as a welcomer at the door. He’ll often be at the door at [the local theatre]. And they like that. …They’re ‘people’ people. They’re social. So, it’s almost your welcoming things that I see as a strength that they have….I just, I think I see them as door people. Umm, because often their coordination and whatnot is a bit difficult at times and so therefore a standing position where they can just speak and welcome.” B_COMMUNITY MEMBER_2</td>
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<td>3. “Here people kind of have a mindset and a way of thinking. So they might be more apt to label someone with an intellectual disability as being…I don’t know if it’s just lack of saying something properly, but they’d be ore apt to, say, use the term ‘they’re retarded’, or ‘they’re handicapped’ as opposed to talking in terms of intellectual or developmental disabilities….And I don’t know if it’s a case of them being, like, using a negative connotation or if that’s kind of the only work they know for it.” B_COMMUNITY MEMBER_5</td>
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<td>4. “I notice sometimes the kids tease. I’ve seen them tease some of the adults. But, at the same time, I can say, I was walking downtown last summer with my dog at night and one of the adults from the [name of agency] group was walking downtown and one of the kids had biked by and made a joke and had made a comment to him. And one of the other kids in the group, the last kid on the bike went up to his friend and said, ‘Hey! Leave him alone! You shouldn’t be talking to him like that!’ So, like, that was kind of nice to see. It was</td>
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Table H-2b: Significant Statements by Community Members in Town B

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<td>nice to see someone in their own peer group turn around and tell them, you know, ‘Don’t be making fun of him’ or ‘Don’t be saying that’. So, maybe we’re starting to see a change which would be good.”</td>
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<tr>
<td><strong>B_COMMUNITY MEMBER_5</strong></td>
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<tr>
<td>1. Re: opportunities for young adults with intellectual disabilities “The old ARC Industries thing that we seem to do away with but I think some of those people, I know one chap that I know that’s very adamant that that should not have happened. He always referred to it as his job and it gave him a certain satisfaction in doing the job, having a job to go to and doing it well so I think in some ways we have lost a bit there and if there was some kind of a program similar or better than that one in the future.”</td>
<td>Employment</td>
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<tr>
<td><strong>B_COMMUNITY MEMBER_6</strong></td>
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<tr>
<td>2. “I don’t see a lot of young people with intellectual disabilities actively working in the community, and I wish I did. I really do, because we have a lot. And, if we sat here long enough and looked out, we would see eight or ten at various times during the afternoon walking along the sidewalk. Their jobs basically seem to be to keep their lives going rather than ‘I have to be somewhere at a certain now.’ Now, young [name of young man with an intellectual disability] at the post office collects mail. Obviously that’s his job and it’s important to him. He does it and he socializes while he does it. It’s great.”</td>
<td>Employment</td>
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<tr>
<td><strong>B_COMMUNITY MEMBER_3</strong></td>
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<td>3. RE: employment for young adults with ID “They usually will, again, end up having some sort of service jobs. Like McDonalds or Tim Horton’s sometimes help these people out. And some of them actually make good employees.”</td>
<td>Employment</td>
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<td>1. “I think that some of the more evangelical groups are very open and welcoming to the young people that have some limitations.” B_COMMUNITY MEMBER_3</td>
<td>Role of organized religion</td>
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Table H-3a: Significant Statements by Young Adults with Intellectual Disabilities and their Mothers in Town A

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<td>1. “Yeah, everybody in [hamlet] knows [daughter’s name], so…They’re really, they make a fuss over her.” A_WITH_FAMILY_MEMBER_1</td>
<td>Being known is important but for some the disability label limits being known.</td>
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<td>2. “If I had a disability, I wouldn’t want to live here. I shouldn’t say that. If I knew, like knowing what I know when seeing what I see, I wouldn’t want to be someone with a disability living here because it’s really hard to sort of grow as an individual and as a person. Because people in the community see you as a disabled person instead of, you know, that tall girl with the blonde hair, you know, who likes horses.” A_FAMILY MEMBER_2</td>
<td>Segregation, rooted in the town’s history of having had a large institution, is still evident.</td>
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<td>1. “And we’ve even talked about moving to a community that didn’t have as much, you know, where there wasn’t an institution at one time and where there weren’t all these group homes and everything else, just to get [daughter’s name] away from…. Because she tends to, like I say now, most of the friends she hangs around with, are people with disabilities, because that’s kind of who’s left. And because that’s where the community kind of pushes her that way, you know? And they’re familiar to her so she does what’s easy, whereas she’s quite outgoing and cheery and everything. And if we were in a community where there were, you know, just the odd person with a disability, you know, who happened to be born there – not because there was an institution or group homes or whatever – she would probably have more friends without disabilities and – not that there’s anything wrong with having friends with disabilities- but that’s …But you know, right now, she’s almost forced to make friends with people who have disabilities because those other options are so much hard for her.”</td>
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Table H-3a: Significant Statements by Young Adults with Intellectual Disabilities and their Mothers in Town A

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<tr>
<td><strong>A_FAMILY MEMBER_2</strong></td>
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<td>2. “I always say I don’t believe in integration, because if you don’t’ segregate people to start with, you don’t need to integrate. So that’s sort of my philosophy. It [this town] has to get integrated because it’s been so segregated, and it’s going to take, probably, a couple of generations.” A_FAMILY MEMBER_2</td>
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<td>3. “Where she works, they’re pretty well secluded so they don’t have too much contact.” A_WITH FAMILY MEMBER_1</td>
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<td>1. “My complaint is that there’s just not enough of the work that I need. You know, like, the, you know, the office kind, you know, accounting. That’s, that’s the kind of stuff I need. I need. You know, to further my skills.”…“I don’t know if I want to move to a big city like Ottawa or Toronto. But I might have to if we don’t, you know, if no jobs come up soon. I might have to start considering looking elsewhere”….“Sometimes I feel I should be trying to find a job in a, in the city and getting away from here. But yet, I, I, most of my family is here. And I don’t know if I’d do well in the city.” Have you ever lived in a city? ‘Nope…but I, I just want to find work.”…“I really want a, I kind of want to move, but it’s…But I, but I’m afraid. You know, partially I’m afraid of being by my, being alone, you know. Plus being, and plus I’m afraid of going out without having a job.”…”I should be going looking for a big job, you know, like, in a big city. But my friends and job counselors tell me that I shouldn’t be doing that because I, I have, I would be so stressed out, it would kill me.” A_6</td>
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<td>3. Would you like to have a job? “Some day. I’m not sure doing what.” A_7</td>
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Work is very important for some and less so to others
Table H-3a: Significant Statements by Young Adults with Intellectual Disabilities and their Mothers in Town A

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<td><strong>1.</strong> “Monday in the morning and afternoon, I go to [city]. I work at [name of store]. On Tuesdays I work at the [agency service] in the morning, go to [city] afternoon, and go home after that. Wednesday, the same one. Friday I work at the [agency service] all day. Saturday I go to hockey games. And Sunday I go to church. Thursday I work at [agency store]. No, no at the child center… on Tuesday and Thursdays. Not [the city] in the afternoons.” What do you like best about all these things? “[name of store in the city]” A_5</td>
<td>Patchwork of activities fill a week</td>
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<td><strong>2.</strong> “Mondays are off…Tuesday…at the lunch program in the morning…and Thursday…and she takes food handling course the afternoons of Tuesdays and Thursdays…Wednesday morning, she’s at the library…Wednesday afternoon…another course, watch soap operas..she’s at home…Friday it’s the same thing. Library in the morning. And then she’s off the rest of the day.” A_WITH FAMILY MEMBER_1</td>
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1. Would you say that people generally enjoy living here? ‘Yes’ Do you? “Umm. Yes, but I wish that, I wish there was more, more stuff here. You know, leisurely and in work, for work.” …“I really, I want to go places. You know, like I did last night (went to the city to watch a sporting event). I want to hang out with my friends….until last year, I didn’t travel a lot. Then last year I finally started travelling, and I haven’t looked back since. And this place, and this [agency] was a big help. We went to a (sporting event) last year. It was my first (sporting event)’s trip I’ve ever gone on, because my family hates, is not a big, are not a big sports fan.” A_6


Quiet is appreciated but some find the town lacking while others are quite satisfied especially as they have
Table H-3a: Significant Statements by Young Adults with Intellectual Disabilities and their Mothers in Town A

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<td>3. It’s fun living in [name of town]. Because there’s lots of stuff do in [town] and [nearby city]. Like there’s lots of movies and places to buy movies…And I love to shop in [town] and [nearby city].” A_4</td>
<td>access to a nearby city for additional amenities. The women appear more satisfied than the men.</td>
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<td>4. “I LOVE living here.” A_5</td>
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<td>5. What do you do with your friends when you get together? “We go shopping; go out for lunch and stuff.” A_2</td>
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1. “Most of my friends are from out of area.” From college? “Uh, not just college. Some of them, some of my other friends you know, I talk to online.” Have you met them or just online? “Just online.” How long have you been connecting with people like that, with the Internet? “Uh, for a couple of years. How do you find that? Uh, it’s okay. But it’s very hard finding friends.” A_6

2. “I do email and stuff” (re: connecting with friends)…”I have a friend that lives in [town], and I have a couple of friends that live in [nearby city; NOTE: went to high school in nearby city]. How did you meet them? “Just by email from school and stuff.” Do you go to [nearby city] to visit them? “Just email.” A_2

1. How often do you spend time with friends? “I go to [city] once a month and go visit [former landlord] once a month in [city]. But I don’t stay overnight. I just go to see her for supper sand stuff and come back home. Because she don’t have any roommate now…. I see [staff] at work every day. And I usually go to her house...” A_6

Staff/landlords are seen as friends/family.
Table H-3a: Significant Statements by Young Adults with Intellectual Disabilities and their Mothers in Town A

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<td>sometimes to have supper.” A_4</td>
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2. *Who do people with intellectual disabilities turn to for advice or to share good news?* (mother) “Well, I guess it depends. I mean those who have family, might be family. A lot of them, it’s staff.” A_FAMILY MEMBER_2 (also a STAFF)

3. *Re: close friends* “She considers the teachers, the people that work [at the agency], as much her friends…. [The agency] has been with [name of daughter] since she was two and a half years old so …They’re as much family…*(daughter adds) ’Best friend’.*” A_WITH FAMILY MEMBER_1

4. *(mother)* “She’s known [name of woman] since she was two and a half years old. And she worked [at agency]. Now she’s retired, but she still…And she has…[name of woman] takes her Christmas shopping for mom and dad. And takes her to the movies. And she’s basically become part of the family. That’s the way it is around her. You really are a part of the family. *(daughter adds) ’Best friend’. ’* A_WITH FAMILY MEMBER_1

5. *Re: Who individuals with intellectual disabilities turn to for advice or to share good news* “Probably their friends and their case manager. It’s sad sometimes because that might be the only friend they’ve got, you know, to them we’re their friend. We know we’re not, and we have to keep telling them that. Sometimes we’re all they’ve got.” A_STAFF_3

1. “I get treated very badly around here”. *By whom?* “Teenagers who think they’re cool.” A_3

*Interactions*
Table H-3a: Significant Statements by Young Adults with Intellectual Disabilities and their Mothers in Town A

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<td>2. “When I was young, I was treated like bad and students being picked on by bullies and being picked on by people. And I didn’t like people picking on me, bugging me and calling me names and calling me not nice names.” <em>Does that still happen now?</em> “No, it doesn't now. But it used to when I went to school. It happened to me.” A_4</td>
<td>with teenagers and as a teenager have been negative.</td>
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<td>1. How often do you see [your parents and younger brothers]? “Every Sunday…I usually stay there (nearby hamlet) every other weekend and I stay with my parents…I see my aunt when she comes and cuts my mom and dad’s hair and she cuts my hair sometimes at my mom and dad’s when she comes to do their hair….I do like to be a part of the family.” A_4</td>
<td>The importance of family ties.</td>
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<td>2. <em>Who do you turn to for advice?</em> “My best friend - my mom.” A_WITH FAMILY MEMBER_1</td>
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<td>1. <em>Re: making friends</em> “Having jobs; I mean, a lot of my friends, I’ve met through jobs too, even if I still don’t have that job. So, you know, I hope she keeps her job at the [store]. She loves it. And same with the [in home business]. You know, there might be a customer that she really clicks with and makes friends, so …I mean, this is why I really encourage her to do a variety of different things, not just, you know, one full-time job.” A_FAMILY MEMBER_2</td>
<td>Recognition that employment could/should offer more than doing work.</td>
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<td>1. “[Name of Group] in [the nearby city] puts on bowling, floor hockey, and baseball. So, but nothing like that here in [the town]. It’s segregated. But you know, there’s nothing segregated or non-segregated in [the town]. It’s better than nothing.” A_STAFF_2</td>
<td>Segregation</td>
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<td>2. “I support a lady at an aerobics class. Mostly I just drive her there and I am there sort of out of sight, just in case she does have a problem or whatever. I’m there. Recently, umm, another agency has started supporting three people with disabilities in the class. So now the person I’m supporting isn’t really part of the class anymore. They’ve all, all the people with disabilities have gravitated to the back of the room. And yet [name of client] had been making friends. And those other ladies would make sure she got the matching weights, you know, not a six pound and a two pound. They’d say, ‘Oh her, you need this one’ you know? And like I just kind of kept right out of it. And they’re like ‘Hi, how are you today?’ or ‘where were you last week? We missed you!’ and that’s changed since these other people with disabilities have come. And it’s not that I don’t want them to come, it’s just, you know...It’s, you know... And I see that happen all the time is that you get clumps. And the gravitate toward each other because it’s comfortable and familiar and they’ve known each other since they lived at [the institution] or they’ve known each other since elementary school.” A_FAMILY MEMBER_2 (also a STAFF)</td>
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<td>3. <em>Do young adults with intellectual disabilities tend to access these places (theatre, arena,...) as a group of people with disabilities or alongside other people?</em> “I think a group of them together, like friends, because they’re similar, their interests are the same. But, I mean, it wouldn’t just be a move night for people with disabilities. We do have segregated dances that people from (the agency) go to and that it, but, I mean they can</td>
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Table H-3b: Significant Statements by Paid Caregivers of Young Adults with Intellectual Disabilities in Town A

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<td>access the bars, you know, the restaurants, its’ you know. And they do tend to go in their little groups, like their friends.” A_STAFF_4</td>
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<td>1. <em>Re: what is needed</em> “Maybe more connections with other people in the community. Volunteers, that sort of thing. But then the people we support get perceived as charity cases, right? So you hire a volunteer to work with somebody or personal support workers. You don’t want to have that, umm, that stigma attached to them. There’s enough stigma already just seeing that they have disabilities.” A_STAFF_2</td>
<td>Stigma result of town’s experience with the institution of the past.</td>
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<td>2. I think we have stigma because we had [the institution’s name] here for years. So there’s stigma that goes along with someone with a disability.” A_STAFF_4</td>
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<td>3. “I find it’s really difficult to, to sort of get members of the community to understand that, you know, they’re not ‘kids’, you know, that they’re just people wanting to live here, customers or whatever, you know?” …”I think that’s partly why they’re treated like children, just because they’ve always sort of been here, you know, maybe more in the background. But they’ve always been here and they’ve always had, you know, little trips into town and the van would come into the store and six people would trot around with staff. And I think that feeling has persisted that ‘the kids’ have come in to the shop, you know, even though ‘the kids’ have long since grown up…So I think it’s very hard to change that attitude.” A_FAMILY MEMBER_2(also STAFF)</td>
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### Table H-3b: Significant Statements by Paid Caregivers of Young Adults with Intellectual Disabilities in Town A

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<td>1. “There are people that don’t appreciate having people with disabilities around – ‘the kids’ as they call them...You’ll be at [name of store] and, uh, you know, helping somebody get some change together. The one time I was helping someone drop off a roll of film to get developed. And the lady at the cash looks at me and says ‘what’s his address?’ And I looked at him and said ‘what’s your address?’ And he told her. She looked at me and said ‘what’s his phone number?’ I said ‘what’s your phone number?’ And he told her....and not to suggest that she didn’t want him in the community, but may just not be sure how to interact or engage, engage him.” A_STAFF_2</td>
<td>Community members experience discomfort when interacting with adults with intellectual disabilities.</td>
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<td>2. “I think if I was to fall down and hurt myself, I would get more reaction maybe than say if somebody fell and was having, you know, someone with a disability was having a seizure and fell out of a wheelchair. Stuff like that. Sometimes it’s hard for people, I find, to approach. If you’re not at that comfort level.” A_STAFF_4</td>
<td>Access to the community leads to acceptance which leads to reduced perception of</td>
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### Table H-3b: Significant Statements by Paid Caregivers of Young Adults with Intellectual Disabilities in Town A

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<td><strong>A_STAFF_1</strong></td>
<td>difference.</td>
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<td>1. “So a lot of it <em>(re: how people with ID are treated)</em> depends how the town gets to know that person, sort of their reputation. And their family too. Umm, if their family has a decent name…again, small town stuff, a lot of it goes with name.” A_STAFF_2</td>
<td>Being known and being from a family that is respected.</td>
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<td>2. “I would say people with intellectual disabilities are treated well if they’re known in the community. So that would be people who live independently, who live, umm, who are independent, that people in the community would see often. Other people that receive support from us, umm, that don’t have as much access to the community or have higher needs are maybe not, they’re not as well-respected. They’re not, you know, if they were to go to Tim Horton’s and, receiving support from myself, the clerk would likely address me before the person that I’m there until I would say, ‘Tell the person, you know, tell the lady what you want’ I would always get addressed first. So, but I mean they’re not, I, they’re treated well beyond that but they’re not given a lot of respect, I would say, unless they’re independent and they’re in the community all the time…” A_STAFF_1</td>
<td>Those who live independently are more likely to be recognized. With recognition comes respect and concern.</td>
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<td>3. “They’re recognized. Like you know, somebody will say to me, ‘Oh, I saw so and so on the street and they’re not looked after.’ They are looked out for. And if somebody has a worry, they’ll say something to anyone of use that they know work her. Like, ‘I saw so and so on the street, you know, I was a little worried about him.’” A_STAFF_3</td>
<td>Conformity</td>
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<tr>
<td>1. “Some churches have told people we support, ‘don’t bother coming.’ Umm. Some have taken them right in. One</td>
<td>Conformity</td>
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Table H-3b: Significant Statements by Paid Caregivers of Young Adults with Intellectual Disabilities in Town A

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<td>lady that attends a church in [hamlet] and, you know, she’s involved in all sorts of things. But that church, the people, invite her out for dinner and, umm, ‘we’re going up to the casino. Do you want to come up with us?’ Some people really connect and make that click. Umm, then other people, like [name of client] or somebody else I support may have a hard time, umm, socializing.” … “There’s a lady, like I say, that goes to [hamlet]. Very accepted, very welcomed. I guess their behaviours conformed to the notions of other people so they’re accepted. And if they don’t they’re not.”</td>
<td>leads to acceptance.</td>
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<td>1. “I find people that are religious-based are more accepting of people with disabilities” …”People (with disabilities) attend church services,…there’s a couple of ladies that I support that, you know, go away for weekends for ladies’ group..”</td>
<td>A sense that religious organizations should be and are more accepting of persons with disabilities.</td>
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<td>2. “I know a number of people (with intellectual disabilities) that go to church. And a lot of churches will provide transportation for the folks to get to church. They will provide somebody to be with them, like in the service, or if there’s a social thing after. They’ll go to that with them and bring them home. I know that happens quite often. If the church can’t be supportive, you’re in trouble (laughter).”</td>
<td>A sense that religious organizations should be and are more accepting of persons with disabilities.</td>
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<td>1. “We have one young man who goes around and, you know, breaks down the cardboard and…He’s not asked to do it. He’s not given anything in return. He just does it.”</td>
<td>Favours and reciprocity</td>
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<td>2. “There’s a lady that owns a campground and usually once a month in the summer, she’ll pick him [client] up</td>
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and, you know, he’ll help clean up the grounds and they’ll have a big barbecue and, you know, he meets all the campers form all over …[Client] does preserves all the time and, you know, she’ll share it with her neighbours and they’ll like share things around with her. So, yeah, it (doing and receiving favours from someone with an intellectual disability) does happen.” A_STAFF_2

1. “One lady (with an intellectual disability) moved into a building and her neighbor comes out to bowling night with them. You know, she’s in on movie night. I mean, we could pretty much not be in her life any more. Her neighbors have really rallied around her that much.” A_STAFF_2

1. *Is it safe for persons with intellectual disabilities to be out at night?* “Maybe in the early part of the evening. It depends. Like in the summertime, I would say no. There’s too many young kids on the streets that are really disrespectful.” A_STAFF_3

2. I think if someone with an intellectual disability was out late at night, walking down main street, they could be a target for , you know, umm, teasing and harassment. And they would be primarily from the younger population.” A_STAFF_1

1. *Re: employment opportunities for adults with ID:* “There may be opportunities. See the hard part of being a small town is, let’s say [staff name] works her butt off, gets [client name]’s a placement at a garage, because he said he’d like to do mechanical sort of stuff. And he pisses off the garage owner. [Client name] will never work in another garage in the [town]. I mean, there’s a handful of them and his name will be mud all the way around. Limited paid employment for adults with intellectual
And by association, her [staff] name will be mud as well. So, there are opportunities. You sort of, huh, you know, you cherish the opportunities like a gem and you wait for the right person to come along. And you hand it to them…We call that setting people up for success. Yes, that’s the euphemism we use! And, umm, a lot of people go to [the nearby city]…You should be able to find local solutions for local problems. I don’t see why we don’t. But that’s not my call.” A_STAFF_2

2. “There’s not a lot of paid employment in the [town] (for adults with intellectual disabilities). We have, of course, our high times which is the summer. Other than that, we struggle with the winter months. We don’t have a lot of paid employment. We have a lot of community placements.” A_STAFF_4

1. Re: what is needed “A bus service or a taxi, you know, some type of accessible, available, reasonable service.” A_STAFF_4

2. Re: what is needed “I would say the priorities are the same. I think there’s other young people without disabilities that struggle, umm, finding ways to get to places and finding good and interesting things to do, you know. “…A lot of reasons they’re not able to access them is because they don’t have transportation.”… “I think the needs (for transportation) are the same whether you have a disability or not.” A_STAFF_1

1. “A perfect example (of people with intellectual disabilities being part of the community) is one of the folks that we supported passed away. And half of the businesses in town were closed that day to attend his funeral. So the church was packed. The outside was packed. People standing outside. And that some somebody we supported...
Table H-3b: Significant Statements by Paid Caregivers of Young Adults with Intellectual Disabilities in Town A

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<td>who was definitely part of the community.” A_STAFF_3</td>
<td>Whether</td>
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<td>Significant Statements</td>
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<td>1. “…a lot of them are in group homes and we don’t see them. But there are some that you</td>
<td>Perception that seeing is knowing and accepting.</td>
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<td>see, right, that have been out there and are known and accepted. I would say, though,</td>
<td>Those more dependent are less likely to be seen and are</td>
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<td>that some people joke around with them a little bit, but I don’t think there’s a level</td>
<td>typically seen in groups “always with their own’ or with staff.</td>
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<td>of harassment or anything like that. And people try and help them, so…I would, I</td>
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<td>would think that the community adopted some of them, almost as part of our Main Street</td>
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<td>culture.” A_COMMUNITY MEMBER_5</td>
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<td>1. “There’s another character who’s around all the time: [Doug] and his bride. [Doug]</td>
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<td>collects bottles and recycling stuff. And you see him all over town with his wagon,</td>
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<td>through all kinds of weather, collecting recycling. He recently…I think again a year</td>
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<td>or two ago, another intellectually challenged woman, they decided to get married. All</td>
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<td>the community was SO happy for them, and…They had their wedding at the [name of hall].</td>
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<td>And other than that, most of the challenged people are always with their own…In the</td>
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<td>stores and stuff, you see them, they’re with workers, helping them. And that’s kind of</td>
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<td>my only contact.” A_COMMUNITY MEMBER_4</td>
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<td>2. “There’s this [name of workplace] that’s right by the gas station. Geez, any time I</td>
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<td>’ve been there, it looks like a beehive of activity. There might be fifteen people</td>
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<td>working there. And I know that on their breaks and so forth they go over and get pizza</td>
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<td>at [local pizzeria]. They certainly are seen on the street. And, by and large, the</td>
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<td>majority of people say hi to them and talk to them and they’re generally in and around</td>
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<td>the gas station talking to motorist.” A_COMMUNITY MEMBER_3</td>
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<td>3. Speaking of Dale, a former resident of the institution now deceased: “And here he was,</td>
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<td>you know, years and</td>
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Table H-3c: Significant Statements by Community Members in Town A

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<td>years later, lived totally by himself. Kept his house absolutely spotless, clean. Hard working guy. And, uh, just a really, really nice guy. And always a smile on his face. He would always be there willing to help out…” “I knew him for the first four years I was here. And I was just scratching the surface with the guy. And he was, a lot of people, he was well known. When he passed away, he was on the front page of the paper and everybody. And I think even the headline said, you know, ‘[town] lost one of its greatest citizens’, you know?” A_COMMUNITY MEMBER_3</td>
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<td>1. “There’s a gentleman…[Foster]...and, uh, he’s still alive…He grew up in [hamlet]. And [hamlet] community accepted him very well and looked out for him. He bicycles everywhere and sells tickets on every raffle going. And he has been accepted very well in the community, extremely well. Taken under the wing of the [local] hockey team and does their equipment managing. And he, he is an example of someone who has been very well-accepted in the community…I think somehow the chemistry came together. The right people were there. [Foster] has a very out-going personality.” … “Like [Foster] just loves people so he’s out all the time. And he goes to the coffee shop with the guys and he does everything everybody in our community who wants to be socially busy does.”…”[Foster] lives right in the village. And he can bicycle anywhere. We have people with intellectual disabilities who live out in the country. And unless some body’s going to drive you, you’re not able to do that. I mean, if [Foster] wants to go and have coffee with the guys, he walks or hops on his bike and does it. But if you live five or six kilometers out in the country and you want to have coffee with the guys and the gals in here at Tim Horton’s and you don’t drive, it’s not likely going to happen. And so I think transportation independence (less obviously disabled) leads to frequently being seen which combined with conformity leads to acceptance.</td>
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<td>1. &quot;I think by and large, the majority of people here sort of keep a special eye out for when they see them (persons with ID) in the community. If anyone is harassing them if they’re on their way back and forth from work or out in the community, generally the people are very quick to sort of jump in and sort of say, ‘What Teenagers are disrespectful but concerned&quot;</td>
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<td>2. “I think for the most part, they’re very well treated. Umm, last year, we had a fellow die. His name was [Bobby]. And, umm, [name] was, umm, a former, a person from an institution. I knew him when he was institutionalized and then he lived in the community. And he died…I can’t just exactly remember. But an overflow at his funeral, and umm he was well-loved and well-liked, and I know that the place where my daughter works…He was in there every day, and you know, he was part of their work community and their social community, and umm they were devastated when he died. And we’ve had similar other things…another fellow who was very involved in the community and fund-raising and things like that – [Dale]. And again he died, you know, it was just like an outpouring of community sympathy. And it doesn’t just happen when people die, of course. When you go to Tim Horton’s there’s often a group of people there who are intellectually delayed. And they’re not treated any differently than anyone else that I can observe. For the most part, I think this community does very well. I think that maybe the problem comes with people who are more obviously disabled, people with, umm, kind of aberrant behaviours. That’s a little harder for people to cope with, but people cope.” A_COMMUNITY MEMBER_2</td>
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A_COMMUNITY MEMBER_1
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<td>A_COMMUNITY MEMBER_3</td>
<td>adults intervene.</td>
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<td>1. Re: local churches “I do know that that’s one area where people with intellectual delays are welcome. And, umm, welcomed as individuals…As a group but as individuals.”…”I have a student who is involved in, umm [name of church] and people pick him up and take him to special events and things like that.”</td>
<td>Adults with intellectual disabilities receive and do</td>
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<td>2. “There are two people that I know. Not on a regular basis, but maybe every sort of couple of months, I’ll stop and talk to them on the side of the road and see how they’re doing, just because I can tell by looking at their face, that they seem to be under some kind of sort of distress. And when I ask them what’s bothering them, generally, it’s they’ve been teased by some of the younger, the younger crowd. Not generally the high school students, but maybe like the junior high, the grade seven to nine students have been sort of bothering them, name-calling, and so forth.”</td>
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<td>3. “We had an instance with a fellow who was…tormented by some young people. And it was kind of an ongoing thing and it was one of those vicious circle kinds of things because he would get angry and then he would react and then it would just, you know, that would feed on each on the whole situation. But people in the community would try to intervene. So I would say yes. I think there’s a sense of (looking after people with ID)…Especially for people who are, who are vulnerable.”</td>
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<td>2. “Every Saturday, [Bobby] would help him (young man who owns the video store) with garbage and then he and [Bobby] would go out for breakfast together.” A_COMMUNITY_MEMBER_2</td>
<td>favors from others.</td>
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<td>3. “...One particular guy that I know that sort of independently that does <em>(do favours for others)</em>, uh, lives by himself and he uh you’ll see him going through town. His name is [Owen]....If you did try to speak to him he won’t say a whole lot because he sort of just keeps to himself. But he will literally shovel the entire length of the sidewalks from one end of Main Street all the way to the other end. And he’s constantly going around picking up garbage, small pieces, big pieces, and going through and going through all that. He does it on a regular basis. There’s another guy named [Doug]. And he certainly is a little more vocal and always has a big wave for you. ...he collects bottles and recyclables and he goes through the garbage cans looking for recyclables. But he also goes through the parks where if the kids throw pop bottles in the park here, he’s there cleaning up and cleaning up the park. [Doug], I mean you know, he’s helping keep the park clean so I guess he’s doing all of us a favour. He’s doing the community a favour. And [Owen], when he’s cleaning up and taking care of the sidewalks, he’s doing it for the businesses. And nobody pays him to do any of that.” A_COMMUNITY_MEMBER_3</td>
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