

Experiencing disability in three small New Brunswick Acadian communities

Dr. Mario Levesque

Department of Politics and International Relations Mount Allison University

malevesque@mta.ca

Abstract: This study examines the day-to-day experiences of persons with disabilities in three small New Brunswick Acadian communities where little is known about the challenges and opportunities they face in daily life. While we can piece together a narrative from studies of rurality, its applicability is far from certain. This research examined (1) how and to what degree their needs are being met; (2) their personal and social support systems; and, (3) their message for decision makers. Analysis of 23 interviews revealed general consistency with the rurality literature and uncovered the need to more closely consider issues of gender and re-integration in disability policy.

Keywords: disability policy, New Brunswick, rurality, persons with disabilities

Resumé: Cette étude examine les expériences de jour en jour des personnes avec des incapacités dans trois petites communautés acadiennes du Nouveau-Brunswick où on connaît peu les défis et les opportunités qu'ils rencontrent dans leur vie quotidienne. Alors que nous pouvons reconstituer un récit provenant d'études de la ruralité, son applicabilité est loin d'être certaine. Cette recherche a examiné (1) Comment et dans quelle mesure leurs besoins sont satisfaits ; (2) les systèmes de soutien personnels et sociales ; (3) leur message aux décideurs. L'analyse de 23 entrevues ont révélé une cohérence générale avec la littérature de la ruralité et découvert qu'il fallait davantage tenir compte des questions de genre et de la ré-intégration dans la politique d'incapacités.

Mots-Clés: politique d'incapacité, Nouveau-Brunswick, personnes avec des incapacités

Introduction¹

This article examines the experiences of persons with disabilities in three small Acadian communities. Little is known about persons with disabilities in small communities and the opportunities and challenges that they face in their daily lives. However, we can draw upon rural studies to develop an understanding but are unsure as to its applicability to persons with disabilities. A 2007 study by the Council of Canadians with Disabilities found that in New Brunswick disabled persons living in small communities and rural areas were economically challenged by being 2.3 times more likely to live in poverty than their urban counterparts. We also know from Forbes and Janzen (2004) that geography is a determinant of health with people who live in small communities and rural areas less likely to receive personal care assistance and other necessary services. Thus, family and social networks become increasingly important to fill the gap as Keating et al. (2011) point out. Moreover, small communities are often characterized as having traditional values and norms, where there is a lack of anonymity coupled with few resources and response systems (see Fitzsimons et al., 2011; Gething, 1997; and, Tryssenaar, 2002).

How does the above profile fit the experiences of persons with disabilities in small New Brunswick Acadian communities? This article explores this question by interviewing 23 persons with disabilities² in the Acadian communities of Grand Falls, Bathurst and Shediac. It examines (1) how and to what degree their needs are met; (2) how persons with disabilities perceive that they are received in the community; and, (3) the networks that they have developed to meet their daily needs. The key is to see how disability is socially and culturally constructed (see Higgins, 1992) from the point of view of persons with disabilities, which gives voice to a marginalized

¹ I thank Andrew Klain for his research assistance.

² I thank all Interviewees for taking time out of their day to speak with me about their experiences.

group in society who are all too often dismissed by decision-makers (Levesque and Graefe, 2013).

The article proceeds in three parts. The first part profiles the Acadian context and the literature to reveal that it does not focus on small communities per se, but rather on rurality. Three strands within this literature can be discerned with persons with disabilities intersecting with rurality, farming and health care, each of which is briefly reviewed to highlight the extent of our knowledge. Next, the historical disability context in New Brunswick is reviewed and is followed by the methods used for this study. The third section then details the experiences of persons with disabilities focusing on services and supports (programs, aides), personal and social support systems and their messages for decision makers. The article ends with a discussion and conclusion section and finds that the experiences of persons with disabilities in three small Acadian New Brunswick communities to be more or less consistent with what is reported in the rurality literature. While several services are lacking including recreational, housing and transportation, debate surrounds a “fight for” and not a “lack of” services in many cases. Similarly, personal and social support structures are challenged and much depends on family dynamics. Lastly, decision makers remain disinterested in rural or small community disability issues which interviewees found to be frustrating.

The literature

i. The Acadian context

Acadians trace their lineage back to the 17th century French settlers in the Maritimes and have a long history of domination and oppression including expulsion by the British in 1755 due in part to British concerns over their rapid population growth (Arsenault, 1986; Aubé, 2013).

Many Acadians returned yet were forced to settle in the isolated northern and eastern parts of New Brunswick. The ensuing 250 years has been one of a slow march towards full inclusion in the province's economic, social, cultural and political institutions. A notable milestone in this process has been the province's linguistic equality entrenched in the Canadian constitution in 1982 (Arsenault, 1986). Yet the struggle for francophone health, education and other government services continues. For example, changes to the province's health districts in 2008 were controversial given fears the changes would dilute Francophone self-determination and services (CBC News, 2008; see also Bowen 2001; and, Picard et al., 1999). Furthermore, any linguistic accommodation is continually met with stiff opposition from the English language majority (e.g., Lapointe, 2016).

Within this context, little is known about the health status and related services including disability services for Acadians. For New Brunswick, reports are mixed. For example, Desjardins (2003) notes the fact that while the health of the province's Francophone population is improving, it still trails that of the English majority, something which Francophones themselves fail to recognize (Bélanger et al., 2011). Health status analyses between urban and rural communities are however not made. What is notable is the fact that Francophone social capital—developments to overcome historical grievances—positively contributes to better health outcomes (Bouchard et al., 2006) and why any proposed health sector changes are met with skepticism and resistance, as noted above.

At the heart of this are language barriers which are formidable and remain an important determinant of health (Bowen, 2001). Effective communication is a necessity for accurate diagnosis and treatment (Wilson et al., 2005). For example, one has to be able to communicate symptoms and know and use (often complex) medical terminology for effective diagnosis which

includes being able to understand physicians' questions and suggested courses of action for treatment. Knowing such terminology in one language is challenging enough for most people but understanding it in a second language is daunting. Emergency situations only accentuate the problem and create added stress, as well as delays for needed services thus increasing the risk of poor health outcomes. While translators, professional or family members, may help overcome linguistic barriers, they are often not used given concerns of revealing personal health information to others. Simply put, linguistic barriers lead to barriers for access to health care services, for comprehension of health services, for the quality of health services and for satisfaction with health services which lead to poorer health outcomes (Aubé, 2013). Furthermore, as Samson and Spector (2011, as quoted in Aubé, 2013: 1) state, "beyond the role language plays in effectively communicating information about illness, disease and disability concerns, linguistically appropriate services are also an important way to show respect for the service user's culture." Cultural sensitivity training of health care providers is required including language training which is also important for the symbolism that it holds for minority groups in that they can be proud of their language and heritage (Aubé, 2013; Anderson et al., 2003), something which is important in a bilingual province such as New Brunswick.

Within the Acadian population, females are less physically active than are males thus contributing to poorer health outcomes a situation that mirrors individuals, male and female, with functional limitations such as a disability, and with lower education such as that found in rural communities (Bouchard et al., 2006; Bourque et al., 2005). It is in such small and largely rural communities where the historical isolation of Acadians is reinforced and where one finds limited Francophone health services, where funding is limited and where issues of recruitment and retention of staff is acute. This is especially the case in relation to mental health services where

one finds a preference for social support structures has developed rather than formal institutional responses (see Mahmoud and Sers, 2016 for an overview). This preference may be due to the historically higher rate of institutionalization and hospitalization, especially in rural Northern New Brunswick, when compared to Anglophones (Robichaud, 1986). Hence, language and rurality remain significant factors.

ii. Rural areas and persons with disabilities

This strand of the literature largely focuses on three aspects. First, discrimination against people with disabilities in rural areas may be significant (Brown et al., 2011) especially when they attempt to find employment as they face significant attitudinal barriers from non-disabled potential employers. These attitudes include employers fearing negative reactions from customers and having to make significant workplace accommodations along with their associated costs. Reinforcing these attitudes is the fact that the medical model of disability which focuses on one's impairment and societal dependency remains prevalent in rural areas. Education and personal contact have yet been unable to negate such discrimination thus underscoring cultural dynamics. The end result is the underemployment of persons with disabilities thus increasing the economic challenges they face (Gannon and McGilloway, 2009; Bualar, 2014; Jones and Latreille, 2010).

Second, several studies find that discrimination against persons with disabilities in rural areas may be related to reports of their having a lower quality of life. Promoting inclusion is challenging and capitalizing on the strong social networks that minimize exclusion present in rural areas is needed. Promoting inclusion may involve higher participation in volunteer activities, more frequent attendance at community events and stronger feelings as being part of the community (Edwards et al., 2003; McPhedran, 2011; for an alternate view, see Hoogsteen

and Woodgate, 2013). The church is also found to be a particularly important rural actor for persons with disabilities. Individuals who do not attend or irregularly attend religious services are more likely to report depression which reinforces a sense of isolation (Mitchell and Weatherly, 2000; Evanson et al., 2006; Irvine and Lupart, 2006). This finding is significant given the importance of such informal networks in times of large scale restructuring like what northern New Brunswick is currently experiencing with rural out-migration (Fisher Cloutier, 2000; Farmer et al., 2011).

Lastly, a general lack of services is reported in rural areas for persons with disabilities including services related to housing (e.g., Grigg et al., 2004), medical care (e.g., Kent et al., 2000) and technology (e.g., Roberts et al., 2005). Similar reports are found in the farming sector.

iii. Farming/agriculture and persons with disabilities

There is a small but growing literature on persons with disabilities and farming. A good part of this work focuses on specific disability related issues, with many studies exploring the mental health of farmers and their workers in trying to isolate the causes of stress (e.g., Booth and Lloyd, 2000; Gregoire, 2002; Schweitzer et al., 2011), their effects on specific populations such as women (e.g., Carruth and Logan, 2002) that lead to high suicide rates in the sector (Fraser et al., 2005). A second strand of this literature focuses on the reporting of accidents and fatalities and on injury prevention (e.g., Adekoya, 2002; American Academy of Pediatrics, 2001; Fielder et al., 1998; Deyczynski et al., 2013). The gray literature on these topics is also significant as evidenced by provincial, state and national farm safety associations (e.g., Canadian Farm Safety Association, n.d.; Farm Safety Nova Scotia, n.d.). A smaller body of work exists that explores service provision in relation to persons with disabilities which are found to be lacking. Medical professionals tend to situate themselves in larger urban centres which is a

problem that plagues health care services in small communities more broadly as discussed below (Hancock, 1998). The point is that rural residents tend to be economically challenged, are in fair or poor health, and to have more chronic conditions when compared to their urban counterparts and face significant challenges accessing services given the need to travel long distances (National Healthcare, 2007). Complicating matters is the fact that rural residents often face communication challenges when trying to obtain health care information because many rural communities have poor broadband telecommunication services (Hass-Slavin et al., 2005). This lack of broadband is unfortunate because many peer support services can and are often delivered through electronic means (Keninger, 1998). The net effect is to reinforce exclusion and a sense of isolation, points which reappear in the health and rurality literature.

iv. Health and services for persons with disabilities in rural areas

Few studies exist that probe health care services for persons with disabilities in small communities yet those that do report similar findings: a general lack of health care services for persons with disabilities which is attenuated for children with special health care needs (Lishner et al., 1996). For example, Skinner et al. (2007) found that children's disability needs were more likely to not be met due to the lack of services or due to associated financial difficulties confronting families. To address service gaps, rural communities have increasingly turned to the private sector yet costs remain significant. Public transportation services either do not exist in rural communities or are chronically underfunded posing serious problems for persons with disabilities in small communities who must often travel to larger urban centres to access medical services (Gonzales et al., 2006). Addressing rural health care means addressing transportation and broader access issues. The lack of accessible transportation complicates the health of rural

persons with disabilities who already refrain from accessing such services due to economic costs or until it is socially convenient (Gonzales et al., 2006; Lezzoni et al., 2006).

Ideally health care services would be provided in one's community yet this is not always feasible. Persons with disabilities are thus left having to overcome cultural and behavioural differences that exist in accessing services in larger urban centres including having to reveal details of one's private life to strangers which may be very intimidating and may negatively impact their well-being (Schmidt and Strong, 1997; also see the above Acadian context). Accessing health care services in large urban centres also necessitates knowledge of their availability for which rural people do not have. As Hodges et al. (2005) note, a lack of awareness leads to the use of fewer services and a lower satisfaction with the services used. Matters are further complicated when communication between service providers is poor or when there are poor and uninformed attitudes among service providers toward persons with disabilities (Bambling et al., 2007). Indeed, the attitudes and values of physicians and other services providers matter especially if the majority of them are male or from another country (Humphreys et al., 2004). In such situations, the health of women in rural areas may be seriously compromised (Leipert, 2005).

The question for this exploratory study is how do the experiences of persons with disabilities in three small Acadian communities in New Brunswick align with what is reported in the above literature—significant discrimination, the importance of social networks, a lack of services (accessibility) reinforced by transportation and communication issues? To ground this investigation, an overview of the New Brunswick disability context is first provided.

A historical overview of the New Brunswick disability context

A significant portion of the New Brunswick population has had a disability over the last four decades. For example, a full 21% of the population had a disability in 1976. Of note is the fact that the northern part of the province which includes small communities such as Grand Falls, Campbellton and Bathurst had fewer persons with disabilities (30.5%) than their share of the total population (32%) yet had more people with severe disabilities (32.5%; New Brunswick Planning Advisory Committee for the Disabled, 1979). Increased numbers of persons with severe disabilities is significant due to the greater costs encountered with addressing severe disabilities. Since 1976, New Brunswick has had the third highest rate of persons with disabilities in Canada as successive Health and Activity Limitation Surveys (HALS) have identified. This rate has ranged from 15.5% in 1986, 17.7% in 1991 to 14.4% in 2001 and has consistently been 2-2.5% higher than the Canadian average (Statistics Canada, 1986, 1991, 2003). By 2006, the population of persons with a disability in New Brunswick as identified in the Participation and Activity Limitation Survey (PALS) was 19.8%, the second highest in the country, a similar position the province would find itself when the results of the Canadian Survey on Disability (CSD) was conducted in 2012 (16.4%). The 2012 CSD survey also revealed that New Brunswick continued to have a higher percentage of persons with disabilities with severe and very severe disabilities when compared to the Canadian average thus underscoring their tenuous position (Statistics Canada, 2007; Statistics Canada, 2012). Care should be taken not to invest too much stock in the specific fluctuations in the disability rate over the years given the different methodologies used in the surveys including the different definitions of disability; rather, the important point to note is that New Brunswick has persistently had one of the highest rates of disability in Canada and a

higher percentage of those with severe and very severe disabilities regardless of the methodology used.

People with disabilities in New Brunswick also tend to have lower incomes. For example, in 2006, the median income of an adult (15+ years of age) with a disability in New Brunswick was \$16,796 which was 69% of what an adult without a disability earned. This income was also lower than all jurisdictions in Canada except for Newfoundland and Labrador (\$14,761; in contrast, Alberta had the highest median income for persons with disabilities at \$22,378; Statistics Canada, 2007). In addition, people from New Brunswick with disabilities had significantly lower participation (53.4%) and employment rates (47.6%) in the labour force than persons without disabilities (79.4% and 71.7% respectively). Overall, persons with disabilities represented 10% of the provincial labour force. Such results may be partly attributed to lower education rates for persons with disabilities. For example, more persons with disabilities do not have a high school diploma (33.5%) than person without a disability (23.2%) while fewer persons with a disability have a high school diploma (23.4%) when compared to those without a disability (27.3%) (Profile of New Brunswick Labour Force, 2013). Combined, persons with disabilities in New Brunswick are challenged to meet their needs given their high number and lower education, income and labour force participation rates leaving many in a precarious position. For example, most home support services, such as assistance with washing, dressing, meal preparation, homemaking and shopping, in the province are provided through the private sector. They charge user fees for their provision since home support services are not deemed an essential service under the *Canada Health Act (1985)* and are therefore not typically covered under provincial health plans. Private home support services thus have an incentive to focus more so on the profitable services only. Persons with disabilities are often challenged to afford

such fees and, even if they can afford them, services may not be provided especially in rural areas given the poor wages paid to home support workers including the lack of or little compensation for their travels to get to a client where they perform only a few hours of work (Krogh and Ennis, 2005).

Disability policy has a long history in New Brunswick dating back to WWII (Liebenberg, 1994). Prior to this date, persons with disabilities were not to be seen and had little recourse to minimal services that existed and that were largely provided by the church and community groups. The polio epidemic from 1941-1955 changed this in forcing the provincial government to begin providing medical rehabilitation services. For example, a polio clinic was soon established in Fredericton which morphed into a new Polio Clinic and Health Centre in 1955 both of which had the effect of greatly expanding rehabilitation services to persons with disabilities. Important in this process were several charities such as the New Brunswick Society for Crippled Children and the New Brunswick Foundation for Poliomyelitis and Rehabilitation. By 1967, these organizations merged to form the Easter Seals New Brunswick Chapter to address both the continuation and expansion of needed services (Easter Seals NB, n.d.).

By the 1970s, a patchwork of private and public sector disability services were offered. It is this fragmentation that isolated persons with disabilities. Many services were offered as a “privilege” which did little to recognize the rights of persons with disabilities. The services offered were also largely inadequate and suffered from having limited staff that were poorly trained among other things. For the northern part of the province, services were few and far between if they existed at all and even fewer were offered in French, the dominant language of the region, and largely inaccessible given the lack of public transportation. A Planning Advisory Committee on Community Services for the Disabled was formed and tasked with making

recommendations to improve the state of affairs. Reporting in 1979, they recommended a provincially driven hierarchical structure for the delivery of services including establishing a Premier's Forum, charging coordination to the Social Services Department and establishing professional advisory committees along with regional advisory groups among other things (New Brunswick Planning Advisory Committee, 1979).

As New Brunswick celebrated the International Year of Disabled Persons in 1981, many feared that momentum for needed policy changes would stall. A conference was organized in the Fall of 1981 which recommended the formation of a permanent advisory committee mandated to bring forth the concerns of disabled persons. In 1982, the Premier's Council on the Status of the Disabled Person (hereafter "Council") was born. It is this Council that has developed several multi-year "Action Plans" that detail needed changes, alternative solutions, the government departments affected, timelines and budgetary effects. To date there have been at least five Action Plans with yearly updates on progress made. The most recent plan in 2012 continued the work on such themes as education (inclusive, improved teacher training), transportation (expand existing services, develop incentives for private carriers to provide) and disability supports (improve accessibility, consultations to develop). For example, while the services at the Stan Cassidy Centre for Rehabilitation in Fredericton are excellent, the fact there is no coordinated transportation system for persons with disabilities, especially in rural and northern areas, seriously undermines its effectiveness (Premier's Council, 2007). In addition to the Action Plans, The Premiers Council has submitted several issue specific policy recommendations to various government departments. These include the 2003 submission on social assistance policies in the province, the 2005 submission on transportation issues, and the 2008 submission to the

Department of Health for greater consideration of persons with disabilities in the provincial health plan (Premier's Council, 2003, 2005, 2008).

Results from these activities have been mixed. For instance, actions from government departments are subject to government budgetary processes which may limit progress. At times, responses from government departments are to further study issues such as for driver assessments or to support the ideas but are largely thin on actions (such as for action on environmental and chemical sensitivities) or are largely evasive such as is the case for enhanced teacher training for which school boards have repeatedly deferred to the teacher accreditation body. Greater success may have been realized in disentangling services for persons with disabilities from long term care programs for seniors in recognition of the unique needs and goals of each (NB Disability Framework Working Group, 2002, 2003). All this to say that progress is a slow evolutionary process and perhaps frustrating at times but progress does exist as evidenced by the province's Extra Mural Program and the Stan Cassidy Centre for Rehabilitation.

The New Brunswick Extra Mural Program (EMP) was instituted in 1981 as a way to deal with rising hospital construction and operating costs, an ageing population and a shift to longer term degenerative conditions. It is a "hospital without walls" or perhaps more accurately a "hospital-at-home-system", that is, an alternative to "hospital admission and to allow for earlier discharge of patients from conventional hospitals" (Ferguson and Barry, 1992; see also NB Health Council, 2011). It has a headquarters in Fredericton and several regional units. The regional units have increased autonomy over resources and the latitude to ensure individuals receive needed services in their homes or communities. The EMP has a broad mandate including

being an alternative to hospital admissions, an alternative to or postponement of nursing home admission, early discharge from hospitals, long-term care, palliative care, rehabilitation services, and the coordination of support services (NB Department of Health, 2015). Coordinators work to ensure that patients receive needed services including from physicians, nurses, respiratory therapists and physiotherapists. Simply put, the emphasis is placed on the coordination and delivery of needed services in a patient's home or community rather than investing in the construction of hospitals which is expensive thus only those that truly require hospitalization receive hospitalization. Early evaluations have indicated that patients were highly satisfied (97%) with the EMP which has proven to be economically and operationally feasible (Adams, 1987; Ferguson and Barry, 1992). A 2012 evaluation revealed that there was an 85% reduction in hospital admissions six months after the initiation of the Extra Mural Program for a client along with a 55% decrease in emergency room visits (Bustard, 2013). These are significant savings at any time but especially in current times of government restraint (CBC News, 2015).

The Stan Cassidy Centre in Fredericton is a product of the polio epidemic in the 1940s and 1950s. Stan Cassidy, a New Brunswick businessman and engineer, founded the Forest Hill Rehabilitation Centre in 1957 to treat individuals with increasingly complex medical problems and to address societal attitudes towards persons with disabilities. In 1994, the Centre was designated as the facility for treatment of the the most complex neurological disorders (e.g., stroke, brain injury, spinal cord injury, muscular dystrophy, ALS, cerebral palsy, autism) (Stan Cassidy Centre, 2010). The Centre had also outgrown its facilities and plans were made for a new and larger modern facility which opened in 2006 renamed as the Stan Cassidy Centre for Rehabilitation in his memory (Stan Cassidy Foundation, n.d.). The Stan Cassidy Centre and the Extra Mural Program are significant for the province because they represent two prongs of its

three prong approach to health care services: community health services (Extra Mural Program), hospital based services (such as Regional Hospitals) and specialty services (such as cardiac, neurosurgery and rehabilitation (Stan Cassidy Centre) (Stan Cassidy Centre, n.d.).

Research parameters

To assess the research question, interviews with persons with disabilities in the three small communities of Grand Falls, Bathurst and Shediac were chosen for this study. These communities were chosen based on a convenience sample for their geographic proximity to the province's large urban centres (Moncton, Fredericton, Saint John). As Table 1 shows, Grand Falls is over two hours away from Fredericton, Bathurst is similarly over two hours away from Moncton (and even further to Fredericton), while Shediac is the closest of the three to a large urban centre at thirty minutes away from Moncton. The further away one is from a large urban centre, the more challenging it may be to receive needed programs and services thus underscoring the necessity of family and community supports. Thus, one would expect to see greater challenges encountered in Grand Falls and Bathurst than in Shediac. In addition, all three communities are predominantly Acadian (Francophone) as indicated by their mother tongue yet residents need to drive to large urban centres where the mother tongue is predominantly English which may present cultural, as well as linguistic challenges (see Table 1).

Table 1: Community Profile

	Population (no.)	Mother tongue – % French (% English)	Name, population (no.) & distance to nearest largest community (km, time)	Mother tongue of nearest largest community – % French (% English)
Grand Falls	5,706-town 11,081 (including Grand Sault, Drummond, Saint-André, Saint-André & townships)	town - 81.2 (16.5) n/a	Fredericton CMA, 94,268, 230km (2h15m)	7.0 (86.7)
Bathurst	12,275-city 33,484-census agglomeration (includes Bathurst, Beresford, Petit-Rocher, Belledune, Pointe-Verte, Nigadoo, Pabineau & townships)	city - 49.3 (47.0) census agg. - 64.7 (32.8)	Moncton CMA, 138,644, 245km (2h20m) Fredericton CMA, 94,268, 260km (3h15m)	34.5 (61.4) 7.0 (86.7)
Shediac/ Memramcook	10,884	S - 74.4 (21.8) M - 82.1 (15.9)	Moncton CMA, 138,644, S-30km (25m) M-24km (25m)	34.5 (61.4)

Twenty-three semi-structured interviews were conducted either in person or via telephone during July and August 2014 as shown in Table 2. All interviewees were adults except one individual whose parents were interviewed on their behalf. Similarly, of the 22 adult interviews, the parents for 12 of them participated in the interview (e.g., answered questions or were there for social support). While interviewees were predominantly French, actual interviews were conducted in their language of choice with an even balance between French and English. Interviewees were identified through various means including Google web searches of government documents and disability group web sites, suggestions from officials from the New Brunswick Department of Social Development and the provincial chapters of the Association for Community Living and the Canadian National Institute for the Blind. Interviewees were also asked for suggestions for other interviews. Each potential interviewee was forwarded a letter of

information outlining the project and soliciting their participation along with an informed consent form. In total, 28 individuals were contacted with 23 interviews conducted while five individuals declined to be interviewed. All interviews were recorded and later transcribed verbatim in the language they were conducted to facilitate a thematic analysis. To ensure confidentiality and anonymity, their names and personal information are not revealed; rather, they are referenced as Interviewee 1 (I1), Interviewee 2 (I2)....

Table 2: Interviewee Profile^a

	Grand Sault		Bathurst		Shediac	
Interviews (No.)	Req.	Comp.	Req.	Comp.	Req.	Comp.
	11	10	9	7	8	6
French / English (No.)	10 / 0		5 / 2		5 / 1	
Interview Language French/English (No.)	5 / 5		4 / 3		3 / 3	
By Disability Type^a	Req.	Comp.	Req.	Comp.	Req.	Comp.
Physical	8	8	1	1	2	2
Intellectual	1	1	3	3	4	4
Visual	1	1	1	1	---	---
Hearing	---	---	2	2	---	---
Mental Health	1	0	1	---	1	---
Learning	---	---	1	---	1	---
By Severity						
Mild	1		2		1	
Moderate	5		3		4	
Severe	1		2		1	
Very Severe	3		---		---	

^aSee text for disability type classification. Req. = Requested, Comp. = Completed

It is important to note that interviewees varied in their disability. This research was cast as inclusive as possible and followed People First's disability classification to include physical (e.g., multiple sclerosis, muscular dystrophy, chronic arthritis, cerebral palsy, spinal cord injury, fibromyalgia), visual (totally and legally blind, visually impaired), hearing (e.g., deaf, hard of hearing), mental health (e.g., schizophrenia; mood, anxiety, eating, personality disorders;

Alzheimer's, dementia, stroke), intellectual (e.g., Fetal alcohol syndrome, autism, Down syndrome) and learning (e.g., Dyslexia, dyscalculia, dysgraphia, dyspraxia, ADHD) disabilities. While interview requests were forwarded to individuals across the range of disabilities, those with mental health or learning disabilities declined to be interviewed. Furthermore, interviews were requested from individuals that varied in the severity of disability (mild, moderate, severe, very severe).

All interviewees were asked questions pertaining to (1) services and supports used (programs, aides); (2) their personal/social support systems via their family and community; and, (3) their message(s) for decision makers. What follows is a synopsis of their experiences which quotes them at length in order to give them voice. All quotes have been translated into English for this journal's audience at the time of manuscript preparation by the author who is bilingual.

Experiences of persons with disabilities in small Acadian New Brunswick communities

i. Services and supports used (programs, aides)

There were several services and programs used with people being satisfied overall though several needed improvements were noted. Services and programs repeatedly discussed included attendant care or support workers, the provincial Extra Mural Program, and the Stan Cassidy Centre in Fredericton.

Attendant care or support workers are an integral part for people with disabilities to maintain their independence by living in their own homes. These individuals perform various tasks such as housecleaning, cooking and personal hygiene. They are also important in helping individuals attend medical appointments and assist them in their shopping needs (e.g., food, clothing) and are especially valued as a source of transportation. Support workers also help take

individuals out so they may participate in various activities such as a walk or hike, attend a movie, play games, go to the gym, attend dance classes, or for simple pleasures such as going to have an ice cream cone. It is this social function that is especially appreciated which allows people to participate in society and build relationships. However, not all interviewees avail themselves of attendant care and support worker services provided through various public and private service agencies and largely funded by the province.

For those that do use the services, on the whole, they noted that they were satisfied with the services and appreciated their efforts. As one interviewee noted, “all the services, we are extremely happy to have them” (I 4, translation by author). Another individual said that the services were “excellent, absolutely satisfied, very, very satisfied and I appreciate them very much” (I 9, translation by author). For parents with children with disabilities, they valued the exposure their children got through participation in the broader community and appreciated the break they got from their child even if it was only for one or two hours (I 4, 7). As one parent elaborated, “[it] is very important for us as we’re getting older, so we got to get a break. That program is excellent and we are satisfied too that they treat us pretty good. My [child] loves going out, really looks forward to it and is usually waiting at the door with their stuff to go out” (I 7).

While satisfied, however, several interviewees noted the fact that a high turnover in staff was problematic. In the words of one interviewee “[t]here is a high turnover of support workers; [they are] only paid minimum wage but [they] need certain courses; usually see three or four times per year turnover; is hard on [my child] especially when young” (I 1). Another parent was similarly concerned as they stated,

we have had six ones [support workers] in past couple of years. It is a problem. You have girls coming on fresh out of school, don’t have the background, don’t have the initiative,

minimum wage, so why go all out? If [you] want persons with disabilities to produce, more [is] needed to have good people to help them (I 6).

These interviewees noted that enhanced wages and training would go a long way to sourcing and retaining good staff members.

Similarly, problems were identified in relation to the identification of services. Where to go? What services exist? How does one access them? It seems that one is largely left on their own to find services as the majority of interviewees noted including one that stated, “You have to know what door to knock on” (I 16, translation by author). This is also complicated by the fact that one has to be constantly looking towards the future for services and needs in that, “you have to be always five feet ahead of them all the time, you have to be demanding and on top of them, it’s a sad life but that’s the way it is” (I 1). This struggle to obtain services was noted by others as well with one stating that,

you really have to fight for the services, not the others that got medical services, I’m the one that got it. I’m the one that insisted I got what they needed; I went to the stores to find out what was out there and was trial and error a lot of times, no one guiding you; had to go by guess and by golly (I 13).

Several interviewees noted that the real problem was a lack of communication which they felt was easy to address. For some individuals, the way forward was “for doctors need[ing] to know more about what is out there or at least be[ing] able to refer you to someone that does know” (I 15). Others saw social workers as key individuals stating that “social workers should guide more, take you by the hand and say ‘we will do this, this and this’” (I 4, translation by author) while noting that caseloads for social workers were too great with them having hundreds of cases (I 7). A government newsletter was also suggested by many interviewees to improve communication because,

no one talks to each other, hospitals, schools, government. They need to share information more and [it] can be as simple as a doctor sends an e-mail to [add them to] a

government newsletter when get diagnosed. Not a long newsletter either, just short bits, bullets, you know, like did you know what's new, what's not. It has to be to the point as busy with kid (I 1).

Interviewees also questioned whether decision makers really listened to them, a problem that living in a small community may exacerbate. As one individual stated, "it's difficult to put your finger on who is responsible. It is not easy at the other end of the [telephone] line to know exactly who to speak with. Is it Extra Mural, the Minister of Revenue or the Minister of Social Development" (I 9, translation by author). Others felt frustrated by the impersonal response they received through form letters from government officials noting that "I have friends in government and so I know how it is. They tell me that you have all different letters for different stuff. They just plugged my name in there and signed it, nothing personal" (I 3). Frustration boiled over at times especially when one had to go back to get a form filled out by their doctor to prove that their child had a disability. As one individual noted, "it is always a fight" (I 8, translation by author). The frustration is real because progress, if any, is so slow with one having,

to educate people, always have to teach them. You always have to start from the beginning but got people [decision makers], they are always about the paper trail, follow the paper trail you know, but life does not work that way (I 16, translation by author).

It is this "following the paper trail" (procedures) that frustrates some individuals to given that they routinely have to wait over six months for approvals for disability supports. In the words of one individual, "I am waiting on the government who is not responding. It is about the red tape that you have to get through but when I need [my device], I need it immediately and not in six months" (I 11, translation by author). Such delays in approvals led people to be very discouraged given they are home bound for excessive periods of time. As they pondered, "I think if this happened to their family, things would move quickly" (I 11, translation by author). This

sentiment was shared by many others (e.g., I 1, 4, 5, 6, 10, 12, 13, 17, 20, 22, 23). Other individuals compared it to an election campaign when politicians of all stripes promise many things for persons with disabilities yet see limited progress, if any, after the election (I 3). This minimization or dismissal of their concerns further entrenches the lack of inclusion in society and makes persons with disabilities feel they are second class citizens.

Other issues are related to employment status. For example, it was also noted that “services seem to be a lot easier to get if not working. If [I am] working, [the government] say[s] don’t need [services] which is untrue as [I’m] trying to pay the bills, not on government dole” (I 3). One’s employment status presents challenges for parents especially if they are single parents. At the same time, a number of individuals noted that they try to avoid using the services and programs or as they stated, “did not use services until they were 20 years old as did not want to go through the system” (I 6). This disuse of services was largely due to not wanting others knowing their personal affairs or to be subject to stigmatization which underscores that work needs to be done to address stigma and discrimination related to disability (I 8).

The province’s Extra Mural Program (EMP) was also noted by most interviewees. The vast majority of individuals noted receiving care under the EMP noting its instrumental role in providing good health care in one’s home. The nurses in particular were singled out several times with individuals noting that they were “hard working” and that they “did not get enough credit” (I 14). A similar response was received for the Stan Cassidy Centre for Rehabilitation (SCCR) in Fredericton which several interviewees mentioned. Individuals from all three communities studied noted that they were really satisfied with the services provided there but questioned its effectiveness. For example, one person stated that the,

Stan Cassidy Centre is a fantastic place. Got virtually everything in one spot and make a whole day of it. So, services [are] good but also more of a social thing. You know you are

going out and will see all these people, dieticians, physiotherapists, doctors but I can't say [it] really helped but learned a lot and it is nice to have that contact (I 19).

The above quote highlights peoples' desire to be part of the community and their desire to participate in daily activities. It also underscores a desire and need for regular social contact.

Transportation or the lack thereof was a common thread in the interviews across the communities. For those having to travel far away such as to the Stan Cassidy Centre (SCCR) in Fredericton, travel was a burden in that it made for an extremely long day or one had to go down the day before in order to not be so tired. A number of individuals noted that travel to and from the SCCR was not paid for by government and the fact that they needed an aide to assist them in their travels (e.g., I 11). Similarly, travel within communities was challenging at the best of times. Disability transit services do not exist in the three communities and individuals are therefore left to rely on friends and family to get them out to appointments or for basic errands. Many really hated this situation because they did not want to continually bother people. Moreover, individuals were at the whim of the schedule of others which made it hard to get what they wanted done completed (I 16, 17, 18). In the words of one interviewee, "It is really, really hard to maintain relationships when I can't get out of the house for 6-7 months of the year. You know, I am not that good with a computer so all I have is the telephone and I hate talking on the phone. So, I depend on people coming to see me which gets less and less as I grow older" (I 16, translation by author). The lack of accessible transportation reinforces isolation. At a broad scale, even though services and supports seem to exist, they are not necessarily available in one's community. Rather, one must learn where and how to access (i.e., "fight for") services for which interviewees noted they needed help with including transportation. Family members and close friends are increasingly relied upon which calls into question the broader personal and social

support systems of people with disabilities in small communities to which we now turn.

ii. Personal and social support systems

Personal and social support can come from many sources including one's nuclear and extended family, neighbours and the broader community, as well as through various disability groups. When probed for systems of personal and social support, a pattern emerged: people either had a dense social support structure or a marginal or non-existent structure from which to draw. Individuals indicating a dense social support structure stated that their nuclear and extended families played a huge role in their daily lives that included their siblings (sisters, brother) and in particular their mothers. Siblings tended to be very protective and exhibit similar behaviour to other persons with disabilities at school and in the community (I 3, 4). Mothers were extremely important and tended to be drawn upon for daily tasks such as babysitting but more so for personal support to help them face the challenges each day brings. Several individuals noted the significant role their mothers played in their lives, a role they deeply missed when they passed away (e.g., I 6, 12).

Spouses were also a source of support for many individuals but tended to be short term. Most people interviewed were single. If previously married, most ended up getting divorced with one person stating that their spouse got up and told them one day, "I am leaving; I can't do this anymore" (I 21, translation by author) which they understood given their spouse was their main source of aid. Years later, this remained a source of great pain for the individual and has caused them to be depressed and to live in isolation. As they stated, "I live in a small town. I don't want to go out as everyone knows you in town" (I 21, translation by author). For parents of a disabled child, the responsibility for the child falls disproportionately on mothers. For example, one individual noted that they had attended a group meeting a few years ago only to find ten other

parents of disabled children there and all were divorced mothers. They figured that “fathers just have a hard time accepting the fact that their child has a disability” (I 8, translation by author).

Individuals indicating a marginal support structure tended to have a fractured family life. In some cases, family members simply did not believe that they had a disability. As one person said, “I have no social support, none, as people do not understand my disability. Its severity fluctuates daily/weekly so [it] depends [on] when they see me. They think I am faking it which makes it really hard for me” (I 15). Matters were worse for those whose family had moved away such as for work (I 11). These individuals felt extremely isolated as did individuals who had recently moved back to the community after being away for years (I 7, 8). For these “returnees”, reintegrating into the community was hard given they were now seen as “outsiders”. Similarly, re-establishing familial structures was challenging given changes in peoples’ lives.

Community support was also mixed. Half the interviewees indicated that they had no community support as it was just too complicated especially when having to constantly educate people about their disability. As they indicated, after a while, you just get tired of it and retreat from society (e.g., I 7, 8, 12, 17). For the other half of the interviewees, they indicated that the community was an important and active social support structure for them. As one individual stated, “they [the community] have been constantly there for anything: hospital, sitters, transportation” (I 6). Community support can also be through passive means such as a community fund like the Fondation Mélissa et ses amis inc. in Memramcook from which those in need can apply to in order to help them meet their needs (I 5).

Lastly, disability groups may also be a source of personal and social support. Most individuals stated that there were no groups relevant to their disability in their community. At the same time, many of them had tried to start such groups to no avail, noting that, for example, “I

tried to get a group going but parents don't want to meet. [There may be] 30-50 families [affected by disabilities] but when call a meeting only get 5-6 out. It's very discouraging. I think they are not interested, it's that simple" (I 7). Similarly, one person said that "I set up a group at one time but after 2-3 meetings, it fell apart" (I 8, translation by author) while another stated that they simply had "no time for extra stuff, I am too busy taking care of my [son/daughter]" (I 3). These individuals also felt that more was needed to coordinate and communicate the activities either in-person or via the internet, something they feel the government should do.

For those individuals that are able to find a relevant group such as the provincial chapter of the Association for Community Living (ACL), they stated that it made a world of difference to them. As they said, "that is when we really started to make progress" (I 13). Another individual noted that,

the ACL is great. I learned everything through them both [provincial] association and national one too. I could talk to people from all over the place and it really helped. For example, ACL was good at school meetings with them as daunting as could have 10 school officials there. ACL was always good at bouncing things off of, ...well why don't you try this or...even when [my child] was ill they [ACL] were there (I 6).

However, they did note that participation in ACL meant that they had to travel a fair bit at times to attend meetings which complicated matters.

iii. *Message(s) for decision makers*

Interviewees were also asked what message they had for provincial decision makers. Three themes quickly emerged. The first is the discrepancy in government support between whether or not your child is kept at home or in a foster home/social housing environment. To quote one parent at length,

the rate of support is not good if child stays at home. You get ~\$700/month in New Brunswick; in Nova Scotia it is ~\$1300/month; but in NB if you place them in a group home they give them ~\$3500/month yet we only get ~\$700/month provided we make

under \$50,000 year. I know this province is, you know, pretty near broke, and I understand that but if you want to compare ~\$3500/month to ~\$700/m, it does not seem very equal. Even if it was just \$1200/month that we got, you would never hear a complaint from me so definitely there is some room for improvement; not to say that I am unappreciative.....we just got a \$100 raise to ~\$700 and it is appreciated, every dime of it...but I only have a limited amount of personal income (I 7).

This point was repeated with another individual stating, “[i]t’s not right. We clothe them; we feed them; their bed, if they need a new one, we pay for it. This costs a lot. I find this not right and they should give the same amount of money to whether they stay with their family or not” (I 8, translation by author). Beyond parents, persons with disabilities stated that they needed more funds to stay in their homes which they noted was far less expensive than setting up large institutions or the alternatives (I 18).

The second theme that emerged for decision makers surrounded transportation issues as previously discussed. Disability transit services are needed in order for communities to be truly inclusive. Interviewees from Grand Falls lamented the loss of the private taxi service which had a specially equipped vehicle. Though expensive to use, individuals were able to go about their errands and appointments without bothering others. When probed as to why the service was no longer offered, they noted that they were told the demand was not there to cover the associated costs, especially insurance. They suggested that the provincial government should subsidize the service either directly to the owner with aid for insurance costs or through vouchers whereby persons with disabilities would pay the regular taxi fare but then the owner could apply to the government for reimbursement for a “top up” to ensure their costs are covered (I 14, 22). A related transportation issue is that of accessibility. There is little point of going out if one cannot access the bank or stores to conduct their business (I 5, 11, 16). More needs to be done to ensure that all public buildings regardless of age are fully accessible for persons with disabilities (I 5).

Lastly, transportation was also an issue for all individuals when one had to go to Fredericton or Moncton for services given lengthy travel times and the high costs involved (I 1, 3, 13).

The third theme surrounds supports for children with disabilities, in particular, enhanced services for teachers' aides and recreation services. Teacher aides were found to be crucial for the integration of children with disabilities in society with individuals noting that they should be supplied equally for all children that require them (I 4). Similarly, recreational services for children with disabilities were found lacking. As one parent stated,

[w]e are not in a big city here. There is a serious lack of recreational programs out there for persons with disabilities but also for any kid that wants no contact and not competitive aspect. We need to seriously rethink how we develop and deliver recreation programs. I really, really hope something is done soon because they need a place, and it does not have to be fancy things either, as simple as having a room in a community centre staffed with volunteers to play games with people (I 3).

The lack of recreational services (supervised) was found to be lacking for adults with disabilities too (I 7, 16, 22).

Lastly, several interviewees noted the need for the province to address assisted housing (supervised) for persons with disabilities.

Discussion and Conclusion

What can we make of the experiences of persons with disabilities in Grand Falls, Bathurst and Shediac? How do their experiences fit with the literature? How can we use their experiences to improve disability policy in New Brunswick?

First, there appears to be a lack of services overall which is consistent with the literature on rurality. For example, many interviewees stated that there was an absence of recreational services for persons with disabilities. They were frustrated with this because it limited their exposure to the community and robbed them of an opportunity to build relationships which the

literature has found to be important for long term quality of life (e.g., Edwards et al., 2003). Interviewees also reported a shortage of attendant care and support worker services especially for taking them or their children with disabilities out for short outings. Such outings are not only an important form of social support for the individual but also for their parents or caregivers because it allows them to spend time with their other children, to catch up on other things that need doing or for simply a break to allow them to catch their breath.

Also consistent with the literature is the lack of accessible transportation services which is a significant barrier to the participation of persons with disabilities in the community. The inability to exit one's home for long periods of time due to a lack of transportation ensures that individuals remain isolated and erodes their mental health (Mitchell and Weatherly, 2000). Transportation issues are significant including for attending appointments both within and outside of one's community yet New Brunswick and especially rural New Brunswick is lacking on this front. Only a handful of accessible transit services exist in the province (Levesque, 2015), and none in the three communities studied—Grand Falls, Bathurst and Shediac. On this, New Brunswick could learn from developments in Nova Scotia where rural accessible transit has grown significantly since the mid-1990s. This has been due to a supportive environment including funding for its establishment and operation (see Levesque, 2015). Similarly, enlisting the help of taxi companies to ensure vehicles are accessible and fares affordable for persons with disabilities, much like what Halifax, Nova Scotia is currently contemplating could also be considered (CBC News, 2016).

Other services in short supply include respite care services (recall, one interviewee is waiting 12 years for such service), housing and various educational aides. The lack of knowledge of available services is consistent with Hodges et al.'s (2005) findings. As they explain, this lack

of awareness leads to the use of fewer services and a lower satisfaction level with the services used. Not revealed in the literature is the “fight for” accessing needed services. Rather, the literature assumes that if services exist, they can be accessed. Our findings suggest otherwise but also that research is needed to uncover and address blockages. For example, for the three Acadian communities studied, language was at times a significant issue when accessing services which has also been identified elsewhere in the literature as an important determinant of health (Aubé, 2013). The fact that half of the interviews were conducted in English as per the interviewees request suggests that factors beyond language are at play. Research to identify these factors and how they may be addressed is needed.

However, what was interesting was that for all of these services the issue was cast not as a lack of services but as a “fight for” services. Most interviewees noted that one can obtain necessary services but that you had to know which door to knock on and be persistent in your demands to the point where it boils over and to not take no for an answer. All noted that such persistence which was time consuming and draining but eventually paved the way for them to receive needed services. This finding is something that was not revealed in the literature.

The literature is also “thin” on program and services satisfaction levels (but see Hodges et al., 2005; and, Flores, 2006). Our results suggest that most interviewees were satisfied with the services that they received, especially with the Extra Mural Program and the Stan Cassidy Centre. Some interviewees went so far as to give high praise to the workers who they see were doing an invaluable job for little pay. Even the high turnover in staff did not generally dissuade them from being satisfied overall with the services. Rather, it created logistical and coordination issues which they found demanding and time consuming. This high satisfaction level contradicts the results in the available literature especially when one considers underlying linguistic issues.

Additional work is needed to tease out the relationship between the degree of language proficiency, ability and satisfaction levels.

Lastly, all interviewees felt that they were not listened to when they called decision makers or contact people. It was more a case of “token” listening where afterwards they would get a form letter thanking them for their inquiry which they found to be very impersonal. Moreover, they found decision makers to be overly bureaucratic often taking over six months to make a decision on technological aides during which time the interviewee is stranded at home unable to go out or to attend to their personal care. Our study did not probe health care provider responses to patient needs and the literature is also largely silent on this. Future work assessing appropriate response types and timelines would be helpful as would an examination of health care provider points of view to better understand the challenges they face.

For personal and social supports, the literature suggests that small communities offer a dense social support structure that includes the family, community, and the church that helps make up for the lack of services (e.g., Farmer et al., 2011). Mixed results were reported from the interviewees. Half of them reported such dense social support structures which they said greatly helped them in their day to day activities. Most also pointed to the central role that their mothers played in their lives and really missed their support when they passed away. Interestingly, those reporting dense social support structures were also the ones that were the most outgoing and extensively involved in community groups (disability or otherwise). For those individuals reporting marginal support structures, the sense of isolation loomed large. They also tended to report a fragmented family structure with siblings working out of province, the fact that they were new to the area or that they had recently moved back to their community. This fragmented family structure is significant as they were also the ones more likely to report being isolated and

often depressed. The fact many were house bound for long periods of time due to inadequate transportation did not help matters. For these individuals, the literature is silent suggesting research is needed to devise ways to break down boundaries imposed by isolation. This is a tall order given the loss or weakening of social capital in communities (see Putnam, 2000).

The fact that most caregivers are single female parents is also not addressed in the literature. This circumstance is significant and imposes a significant workload on these individuals to make ends meet. Disability and gender are culture specific and intertwined. The past 30 years has seen a shift from the medical to the social model of disability. The medical model emphasizes the problem and individualized nature of disability in aiming to rehabilitate or “fix” the individual to facilitate integration into mainstream society. In comparison, the social model of disability views disability as a social construct where it is a product of the social environment and society therefore needs to change to accommodate differences (Levesque and Langford, 2016). Within these viewpoints are questions as to whether or not disabilities are seen as a value or a threat. For example, while Western societies that value equality and independence see disabilities as a threat to their independence and ability to work with changes needed in the social environment, non-Western societies see the threat as one of whether or not one can contribute to social/familial relations for which females play a disproportionately large individualized role (consistent with the medical model) (Ripot and Woodgate, 2011). Matters are further challenged when cultures overlap. For example, Chinese-Americans who live and work in the US nevertheless feel ashamed for having a disabled child for which the mother is typically blamed and is largely responsible for the child’s needs on her own (Chiang and Hadadian, 2007). Our results suggest that this gendering is often forced on the mother given the high divorce rate of our interviewees. That is, the pattern among our interviewees is one where fathers blamed

themselves for having a disabled child, tended to work longer hours partially to minimize family interactions to the point the dissociation contributed greatly to marriage failure. Research is required to better understand male responses to disability given the fact that maintaining the nuclear family may go a long way to improving a disabled person's personal and social support structure.

For decision makers, the message was clear. Interviewees were more than happy to identify feasible ways to enhance services and programs. They only needed to be asked. For example, enhanced communication is required between all agencies which can be provided by a newsletter to which one is enlisted by a physician when a diagnosis is made. The interviewees' experiences also suggested the need for a strong government organizational and coordination role to establish needed support groups. Interviewees also demonstrated a strong sense of equality and understanding of current provincial challenges. This understanding was evident when interviewees elaborated the need for enhanced funding to help keep their child with a disability at home rather than place them in a specialized care facility for which significantly more financial support is currently provided. As they stated, in light of New Brunswick's budgetary challenges (i.e., deficits), they would be very happy with just a bit more financial support and not necessarily equal support to what individuals in neighbouring provinces such as Nova Scotia receive. In addition, equity was also raised when interviewees suggested that services should be provided equally to those in need of them. Rather than one having to fight to obtain them, services should be automatically provided with someone to check up on them yearly to reassess their needs. Lastly, significant work is required on the transportation and housing fronts.

For people with disabilities in the three Acadian communities studied, our results suggest how disability intersects with rurality and language issues. Poor communication of limited services leads to significant challenges to access them including the lack of accessible transportation in and between communities where one is largely served in a language that is foreign to them. This situation reinforces patterns of isolation at a time when they should be turning outwards to meet their needs thus severely limiting the inclusion of persons with disabilities in society and leading to poorer health outcomes. Anglophone resistance and hostility to language and service accommodations in the province further entrenches this isolation in extending the effects of domination, oppression and colonization (e.g., CBC News, 2016b). A renewed provincial commitment to services provision is needed but one that is culturally sensitive and inclusive. This demand may be a tall order for New Brunswick given its challenging fiscal situation but one that is not insurmountable given that small changes can make a large difference as our interviewees revealed (e.g., better communication between physicians and services providers upon diagnosis and changes in health status).

Moving forward, research is needed on many fronts including on fathers' responses to disability, services satisfaction levels and linguistic issues, services accessibility and service provider response types and timelines. Similar research that focuses on the province's three main urban centres, Moncton, Fredericton and Saint John would facilitate a much needed urban/rural comparison. In addition, understanding the experiences of front line service providers such as social workers is equally important. What are their concerns? What do they think should be done? Combined, a better understanding of the challenges facing persons with disabilities in small communities would be developed so as to better inform decision makers so they could make New Brunswick society more inclusive.

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