

Disability, Culture and Service Engagement among Chinese, Somali and Tamil Communities in Toronto

The Roeher Institute

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I. Introduction

The Toronto area has consistently been a major immigration destination in Canada. Forty-four percent of the foreign born population in the country lives in the Greater Toronto Area (GTA), a figure rivalled in proportion only by Vancouver, home to 38% of foreign born Canadians (Statistics Canada, 2003). The United Way reports that while the City of Toronto accounts for 50% of the total population in the region, this central area is home to 71% of new immigrants in the GTA (Clement, 1999).

Such a high proportion of individuals and families of different cultures, languages, beliefs and customs poses a real challenge for social service agencies in the metropolitan area. Service organizations must bring new consumers into their ways of doing business while respecting the needs and boundaries of those consumers.

This dual need appears to be especially important in the area of service provision to persons with intellectual disabilities.

Many divergent beliefs about intellectual disability and mental health issues persist in the various ethnic communities that make up the population of the GTA. Persons who manifest the signs of having an intellectual disability or mental health problem are subject to a wide range of social attitudes based in an equally wide range of what Western science would call misperceptions and false beliefs.

Such beliefs include the idea that intellectual/mental issues are a punishment from or test by God; that they are the result of inhabitation by spirits; that they are caused when a pregnant woman sees or comes into contact with a person with a disability; or that they are caused by poor breeding.

These beliefs bring attention to the different ways different cultures think about intellectual disability and mental health issues. At the same time, “every society has excluded people with disabilities from full participation in every key avenue of community and societal life. Canada has an equally poor record in the treatment of people with disabilities, particularly related to institutionalization, exclusion from access to most social and recreational facilities, [and] denial of basic human rights,” for example the right to marry, to have children, and to own property (The Roeher Institute, 2003, 11).

The history of intellectual disability in this country has shown that the greatest barriers to the community inclusion of persons with non-normative abilities are structural and attitudinal rather than personal. That is, the majority of barriers are located outside of rather than within persons with intellectual disabilities.

Such barriers are no less likely to exist within ethnic minority populations. Ethno-cultural communities experience a range of needs and problems that exacerbate the exclusion of people who are often defined by their differences. These needs and problems may include lack of facility in the English and/or French languages; lack of education and training in viable professions; lack of information about social service agencies, administration styles, and

supports; shortage of contacts in the new country/region/city; and – particularly for refugee populations – post-traumatic stress issues stemming from violence, separation from family, and quick exit from the country of origin.

Also significant are those barriers that find purchase in the policies and practices of the political and social agencies that have as their mandate the provision of services to populations in need. These agencies are the gatekeepers to the resources that are needed by various populations in order to succeed in achieving independence from these very same agencies. Such barriers include labour market discrimination, lack of recognition for education and training achieved outside Canada, a shortage of affordable housing (Clement, 1999, 14), and a shortage of immigrant settlement programs (Reitz & Lum, 2001).

While not all new Canadians experience these problems, it is likely that many individuals and families in need of specialized supports may face many of them.

It was in the face of these cultural and structural issues that Community Living Toronto (CLT) and The Roeher Institute applied to the United Way of Greater Toronto for project funding, in order to examine the needs and experiences of ethnic minority communities in Toronto vis-à-vis intellectual disability. More specifically, the project examined the Chinese, Tamil, and Somali communities in the megacity. The analysis that follows will serve as the final report of this project.

II. Project Description

A. Purpose of the Report

This report presents, analyzes and discusses findings of the project entitled *Intersections of Cultural Understandings of Disability, Service Provision and Citizenship of Persons with Disabilities Belonging to Immigrant Communities*. The report includes: (1) excerpts from the literature review performed for the project, (2) discussion and analysis of surveys examining the beliefs, practices and experiences of parents of children with disabilities from ethnic minority communities, (3) discussion and analysis of the proceedings of focus groups and interviews with individuals who either self-identified as belonging to an ethnic minority group or who provide services to members of such groups, and (4) recommendations and ‘next steps’ for action.

B. Scope and Objectives of the Project

The project addressed two major questions:

1. How do cultural understandings about disability within one’s own community affect the life experiences of persons with disabilities, both within their communities and when accessing needed supports and services?
2. How might the lack of understanding about cultural beliefs and attitudes about disability impede the outreach of social service workers in the provision of needed supports and services for successful settlement and the full citizenship of persons with disabilities from ethnic minority communities?

The objectives of the project were to:

- Gain an understanding of the specific attitudes toward and beliefs about intellectual disability in Tamil, Chinese, and Somali communities;
- Document the experiences of these communities in relation to social service agencies in the Toronto area;
- Understand how these two factors – (1) attitudes and beliefs, and (2) interactions with service providers – affect the lives of ethno-racial people with intellectual disabilities and their families;
- Suggest actions that will aid Community Living Toronto and other service providers to more effectively engage with ethnic minority communities in Toronto.

III. Methodology

A. Research Design

The following steps were performed in the course of the research:

1. A cross-disciplinary literature review to identify studies that examined specific cultural understandings, attitudes and beliefs about disability within ethno-cultural communities, and potential areas of risk to persons with disabilities that arise from them. To this end, a search was undertaken of the York University and University of Toronto libraries, as well as a search of online databases relevant to cultural and social studies, including Sociological Abstracts, Social Work Abstracts, Medline and Expanded Academic ASAP. Search terms including “Somali service,” “Somali disability,” “Somali health,” etc. were used (replacing “Somali” with “Tamil” or “Chinese,” and variations on these) to find research articles that address the issues of service uptake; attitudes toward and perceptions of disability; general attitudes of ethnic minority groups towards North American and European models of health care and service provision; and approaches that have been employed in other service areas and jurisdictions, with particular attention paid to the United Kingdom for Somali and Tamil populations. In addition to database searches, the web was also a valuable source of information for the groups in question.
2. Community consultations to invite engagement and support from the selected ethnic minority communities. This was accomplished through joint interviews with a Roeher Institute researcher, representatives of Community Living Toronto, and members of ethno-specific organizations.
3. Structured interviews with persons providing disability-related supports and services to persons with disabilities and their families to probe for the nature of challenges encountered among specific immigrant communities. Interviews were also performed with the objective of understanding why some traditional service providers had been more successful than others in making connections with and inroads into ethnic communities, as well as with individuals with various ethnic backgrounds, in Toronto.
4. In-depth, written (hard copy or electronic) surveys were created, targeting individuals from ethnic minority communities, as well as service providers. Surveys for individuals were translated into Mandarin Chinese, Somali and Tamil; service provider surveys were administered in English only. Surveys were distributed by Community Living Toronto and Roeher Institute employees, associates of CLT employed by other organizations and/or to ethnic minority communities.

Owing to late revisions, two versions of the family member surveys were distributed to possible respondents. At the time of data entry, the two versions were matched and combined, with the result that four housing-related questions were not included. Survey data were analyzed using SPSS version 10.5.

5. Six focus groups were held with:

- a. Chinese people with disabilities and their families (attendance: 10 individuals and/or family members);
- b. Employees of a large children's centre who specialize in working with the Chinese community in Toronto (attendance: 10 service professionals);
- c. Tamil people with disabilities and their families (attendance: approx. 20 individuals and/or family members);
- d. Members of Tamil service organizations, as well as non-ethno specific organizations who provide services to the Tamil community (attendance: 11 service professionals);
- e. Somali people with disabilities and their families (attendance: 4 family members);
- f. Members of Somali service organizations, as well as non-ethno specific organizations who provide services to the Somali community (attendance: 4 male Somali 'community elders').

All focus groups, with the exception of the session with Chinese families and individuals (conducted by the Institute project director), were conducted by the principal Roehrer Institute researcher, with the aid of Community Living Toronto employees. Focus group participants were identified and invited through contacts with connections to both Community Living Toronto and the populations in question. Participants were invited through personal contact (e.g. in person, phone, email, etc.) as well as through short letters that were translated into Mandarin Chinese, Somali, and Tamil.

B. Strengths of the Research

A major strength of the research was the opportunity it provided Community Living Toronto employees to interact with a diverse range of individuals outside the normal confines of the worker-client relationship. CLT representatives are to be commended for actively engaging in the research process.

The research process allowed the research team to engage with a variety of stakeholders: people who do and do not have disabilities from ethnic minority communities; service providers who are either (a) self-identified members of an ethnic minority, or (b) providing services and supports to ethnic minority groups; members of ethnic minorities who are themselves attempting to change attitudes and beliefs about disability 'from the inside'; and other researchers performing work in the area.

The focus groups met with very positive reactions from participants, and served as a valuable forum – especially in the case of the well-attended Tamil groups – for networking among participants, as well as for the dissemination of the 'community inclusion' philosophy. This format is one that could conceivably be used in the future for further outreach and educational seminars.

A fourth strength is the insight the research has provided into the range and diversity of cultural perceptions of disability. This project adds to previous research which has shown that although attitudes and beliefs about disability are indeed influenced by culture, other factors (e.g. age, acculturation to the dominant belief system, proficiency in the English language, level of

schooling, etc.) can and do play an equal or greater role in explaining differences in attitude and belief.

C. Limitations

While the focus groups were generally well attended and met with positive responses, a major limitation of the research was the length and complexity of the survey forms. Very few members of the Somali community, for example, completed the surveys for these reasons. The Somali surveys that were completed were only done so with the aid of a Community Living Toronto employee. A number of Chinese respondents were aided by research partners with connections in the Chinese community who sat with participants, answering questions and clarifying the meanings of terms used.

Another limitation was the difficulty making inroads into the Somali community. Focus groups were poorly attended; when attempts were made to set up interviews with service providers, many phone calls were made without callbacks. While several interviews were completed, a less-than-optimal representation of the community is presented here.

In addition to the low number of completed Somali surveys, the Tamil population was also poorly represented in this facet of the research. Therefore, section V must be viewed as mainly representative of Chinese individuals who completed the written surveys. The survey results cannot realistically be generalized to the larger population. It may be that those individuals who responded to the request for survey participation differ significantly from those who either (1) knew about the research and did not participate, or (2) did not know that the research was taking place.

Only eleven service providers completed surveys; four of these were employees of Community Living Toronto. This facet of the research provides very little descriptive information and, though the results will be provided to the funders if requested, it is not included here.

IV. Context of the Research

A. Characteristics of Ethnic Minority Groups

The counselling professions have produced a wealth of literature that describes ways of accommodating cultural differences in service/support/therapeutic relationships, and of acting in a way that respects and welcomes people of different cultures. This includes a pragmatic consideration of both long-developed cultural attitudes and of real, everyday worries that face new Canadians.

For example, it has been suggested that the relationships created between service provider and client are as important as the services an organization may provide:

The success of rehabilitation approaches depends on the quality of the relationship and the practice of rehabilitation techniques. Personal involvement, commitment in inducing hope and techniques to improve a person's individual, relational and environmental awareness as well as his or her skill to set goals and create new opportunities are needed (Beimans, 2000).

The initial phase of contact with a potential client is especially important, and "includes issues about communication barriers, family and personal background, and ethnic community. Problems relative to identification present issues of disclosure, information, and understanding. Assessment requires consideration of social-environmental impacts as well as psycho-individual reactions" (London & Devore, 1988, 314).

Of course, before service providers can be in a position to become personally involved in the lives of immigrants and refugees, a basic level of knowledge and trust of a particular service provider must be in place. Without a basic level of understanding, helping agencies will not be welcomed as aides to the settlement or adaptation process. In some cases this may have very little to do with the ability or reputation of specific agencies or services. For example, in a recent Roeher Institute study, researchers were told that one family with a daughter with a developmental disability was resistant to using the association's services because they feared it might affect their daughter's ability to sponsor a potential marriage partner. This is a common issue – the fear of accessing disability services, because of peoples' perception of a detrimental impact on their migration status (The Roeher Institute, 2003, 10).

Families who have been fortunate enough to gain entrance to Canada for a child with a disability may be unwilling to jeopardize their citizenship status by bringing undue attention to a family member who is seen by some official sectors as a high user of resources (several interviewees for the present study noted that families who have children with disabilities are more likely than those without to be denied entrance to the country). This feeling may also extend to families who have children with disabilities born since immigration to Canada.

The same study found that a significant barrier to accessing programs is not unwillingness to use services, but rather a lack of English-language skills. Communication problems can lead to "biased evaluations, difficult communication, limitation in the understanding of instructions, in

interpersonal relations and in the accomplishment of tasks which the person could accomplish in his or her mother tongue” (The Roeher Institute, 2003, 16).

A cultural barrier often mentioned in the literature is the individuality and self-determination that are prized characteristics in Europe and North America. This may be alien to ethnic minorities that are more family and community orientated.

Thompson (1997) has brought to light the different service needs of populations characterized as having *independent* versus *interdependent* views of self. Independent cultures are epitomized by the stereotype of the middle class in the United States, and to a lesser extent Western Europe and Canada. Interdependence, on the other hand, characterizes the dominant cultures in Asia, Latin America and Africa. North American philosophies of service provision that emphasize individualism, self-support and self-determination, therefore, “may limit... effectiveness when serving clients with more collectivistic cultural orientations” (16). These cultures may also take issue with the intrusiveness of outside agencies into community and family life, especially after the rigours of immigration bureaucracy.

Thompson (1997) provides a list of attributes that are likely to be more common in independent versus interdependent cultures. The table below is adapted from her descriptions.

Individualism/independence	Collectivism/interdependence
Emphasis on personal thoughts, feelings, actions	Repressing outer evidence of emotion and personal feelings about the group
Individual expression	Belonging and fitting in
Personal achievement	Promoting the goals of the group
Personal control of destiny (internal locus of control)	Fatalism, belief in destiny (external locus of control)
Individual recognition = respect	Skill in maintaining group harmony = respect
Competitiveness and personal merit, rising above other members of the group	Harmony and flexibility, knowing one’s place in the group

These differences can create problems during a service agency’s negotiations with families of ethnic minority persons with disabilities. Above and beyond the language barrier (which may be more pronounced with older group members), families may have little confidence in a counsellor who is perceived to know little about the group (particularly if they do not know the language); the family may live in an isolated environment and interact only with in-group members; and the community may have its own beliefs and prejudices about Canada and Canadians (The Roeher Institute, 2003, 16).

Thompson (1997, 17) also refers to the behaviour of collectivistic groups in the recognition of in-groups versus out-groups, where the out-group “could include all or most members of the dominant culture.” This raises real barriers for service providers regarded as a representative of the out-group, and could be manifested in a mistrust of public service systems in general.

Cultural differences between service provider and consumer may be exacerbated by the culture shock of seeing people in positions of authority taking an interest in a child who may have

previously been regarded as a burden, or as a charity case, or as struggling to keep up with their peers; many acculturated Canadian families may have the same problem. The Roeher Institute has reported that it may be surprising for some families to have professionals discussing the needs of their child. They may need education on why this is done, so that there can be a process of building trust and understanding roles (The Roeher Institute, 2003, 24).

It is also reportedly common for people with disabilities from ethnic minority communities to hide the presence of disability. This may happen with individual youth or adults who have a disability, or with families who wish to hide their disabled child. Individuals may do this for instrumental reasons: “[Hiding disability] is a heavy burden but they know that the accumulation of a double negative categorization, immigrant and [disabled], does not increase their chance to find employment” (The Roeher Institute, 2003, 18).

On the other hand, generational differences may become apparent when young people (though not necessarily *only* young people) with disabilities take on the philosophy of their adopted country:

Some people with disabilities want to become more Canadian since their culture rejects them. Some see their own family as a real barrier and feel that immigrants with disabilities are vulnerable in their own community. If workers want to help, they have to deal with the family. It is detrimental when parents speak for their children (The Roeher Institute, 2003, 31).

There are likely to be varying degrees of within- and between-group difference within ethnic minority populations. For example, all three groups examined here are out-groups in relation to the culturally dominant white Canadian population, and may have had similar experiences with discrimination and ignorance of their respective cultures. At the same time, there are likely to be great differences in attitudes between young, middle age, and older members of a particular group.

For example, young Chinese males may have much more in common with their white high school peers than with their grandparents. Time since immigration, or birth in Canada, will have an influence. As Sue & Sue (1987, 485) write, “making generalizations about Asians or Asian Americans without taking into consideration subcultural differences can lead to faulty conclusions.”¹

There are also likely to be lines of division within a particular ethnic minority regardless of their relation to the white majority. Judging from the literature, this seems to be less of an issue for Tamil-Canadians, the majority of whose ancestry is from Sri Lanka rather than Tamil Nadu in India, and who share a group identity set off by opposition to and war with the Sinhalese majority population in Sri Lanka. The Somali-Canadian population seems at first glance relatively homogenous (sharing a common official language and religion, and a history of civil war and displacement), but can in fact be differentiated by clan/tribal allegiances, actual (versus official) language, and northern versus southern homeland region (which is tied to clan allegiance). Chinese-Canadians in Toronto have origins in various parts of mainland China,

¹ See also, Howard-Hamilton (d/u).

Hong Kong, Taiwan, and the innumerable other parts of the globe where the Chinese Diaspora has settled.

On the other hand, intra-cultural differences that may have existed in the homeland may not apply in Canada. For example, one interview respondent commented that Somali people have for decades been distinguished by origin in the northern versus southern areas of the province. This was at first a problem for immigrants (it was remarked that the community “lost two years fighting with each other”), but appears to have been overcome and is now a source of bonding between the northern and southern groups. For example, there is much self-conscious joking among northern Somalis about the limitations of those from the south, and vice versa. These jokes are a source of humour, and a repository of what is now a shared history for both groups.

B. Characteristics of Service Providers

A recent study on rehabilitation services in the United States reported that “the statistics of rehabilitation services provided to culturally different populations indicate an alarming number of unsuccessful rehabilitation outcomes. Specifically, there is a high probability that people with disabilities from certain cultural groups will not respond well to, or assimilate to, rehabilitation services” (Wong-Hernandez & Wong, 2002, 101).

The authors expressly note “the need for rehabilitation professionals to become more competent regarding multicultural issues...” and pinpoint the need to employ a more culturally diversified staff, as well as for existing staff to “learn to recognize the cultural values of minority individuals and to adapt service delivery approaches accordingly” (Wong-Hernandez & Wong, 2002, 101, 117).

The Roeher Institute has heard that service providers are often “not aware of the particular needs of immigrants, even in cities where they [are] seeing clients from ethnoracial and/or immigrant communities” (The Roeher Institute, 2003, 39). These particular needs are attributed to the interplay of race, language, culture, and religion.

For example, the needs of older first generation immigrant women may call for a different approach than that required by multi-generational Italian or Ukrainian Canadians. Interactions between members of ethnic minority communities and their new cultural surroundings may inhibit help-seeking behaviours, and may have less to do with a particular cultural background than with newcomer or perceived out-group status.

Rather than viewing such differences as problems that ethnic minority communities must change themselves, many studies seem to indicate that not only is it a responsibility of service agencies to accommodate these different needs, accommodating service agencies can serve to educate such populations through the give-and-take inherent in an accommodating service relationship.

Wang, Sedlacek & Westbrook (2001) write:

The assumptions regarding the characteristics of ethnic minority groups leads to the self-fulfilling prophecy. If clients from other cultural groups are believed to be non-self-disclosing, dependent, in need of structure, direction, advice, and so on, then they will be treated as if these things are

true, and they will respond to confirm the counsellor's beliefs. It is thus assured that standard or traditional approaches will not be effective.

A participant from a disability service organization in a previous Roeher Institute study expressed the difficulty of trying to be "all things to all people." She felt that since her organization lacked understanding of cultural barriers, it should be able to refer clients to another group with cultural expertise. However, often these groups don't have the expertise around disability (The Roeher Institute, 2003, 11). This signals a need for relationships between disability-based and immigration/ethnic minority-specific service providers, both to share information as well as workloads.

As will be discussed below, this need for organizational partnerships was an oft-mentioned solution to the problems Community Living Toronto has been facing in its relationships with ethnic minority communities.

Throughout the research, it was apparent that the organizations involved were aware of the potential shortcomings in their methods of service delivery. While misperceptions and false beliefs were not completely absent, these existed in good faith and were for the most part a corollary of the attempt to understand different cultures. The will to initiate the present project was itself an expression of good faith and an attempt to understand in order to facilitate change.

At the beginning of the project, one commentator objected that the project focused too much on ethnic minority communities themselves, rather than on the need for service agencies to engage in outreach, and to make services accessible in culturally sensitive ways. In response to these comments, it should be noted that the project was carried out (1) as a chance for Community Living Toronto to understand different cultures in order to better serve them, and (2) as a method of outreach based in a framework of inter-organizational learning. The emphasis throughout the project has focused on ethnic minority experiences with the social service system in Toronto.

V. Findings of the Research

A. Survey Results

Of the 48 surveys completed for the research, 11 (23%) were completed by service providers and 37 (77%) by family members of individuals with disabilities. The majority (84%) of individuals indicated that they provide support to the individuals who were the subjects of the surveys; in one case the respondent was the person with a disability supported by other family members; three of the respondents also provide informal support to friends with disabilities. As noted above, due to the small number of respondents, results from service provider surveys will not be presented here.

1. Family Survey – Details

a. General information

The survey was completed by 16 males, 20 females, and one person who did not specify their gender. Of the 37 respondents, 22 were of Chinese, 9 were of Tamil, and 6 were of Somali background. Other relevant characteristics of participants include the following:

- Only 2 respondents were born in Canada; year of immigration for the others ranged across 40 years: 1961 was the earliest, 2002 the latest.
- **Education** -- 86% of respondents had at least some high school education; 68% had at least a high school diploma; 35% had received accreditation at a post-secondary institution (college or university).
- **Current education and employment status** -- 24% of respondents were in school at the time of the survey; almost 50% were employed. **Tables 1 through 3** provide additional information about respondents' participation in employment and schooling.
- Of those who indicated they were working, 61% were working full-time.
- **Marital status** -- The majority (78%) of respondents indicated that they were married.
- **English language proficiency** -- The majority (78%) indicated they could speak and understand the English language.
- Those who receive supports from respondents vary widely in age – the youngest was 6 years, the oldest 82 years of age.
- **Type of Disability** -- 33 of 37 respondents indicated that they provided care to a family member with an intellectual disability (please see Table 4). 26 of these family members have had the disability since birth. Many of those receiving support have more than one disability.
- For the individuals who responded to the question, all but one family member with a disability was currently living at home with the family.
- Families were very unlikely to report problems acquiring enough food for their children; only one family reported ever using a food bank.

Table 1: Respondents currently in school

Currently in School?	Frequency	Percent	Valid Percent
Yes	9	24.3	25.0
No	27	73.0	75.0
Total	36	97.3	100.0
No response	1	2.7	

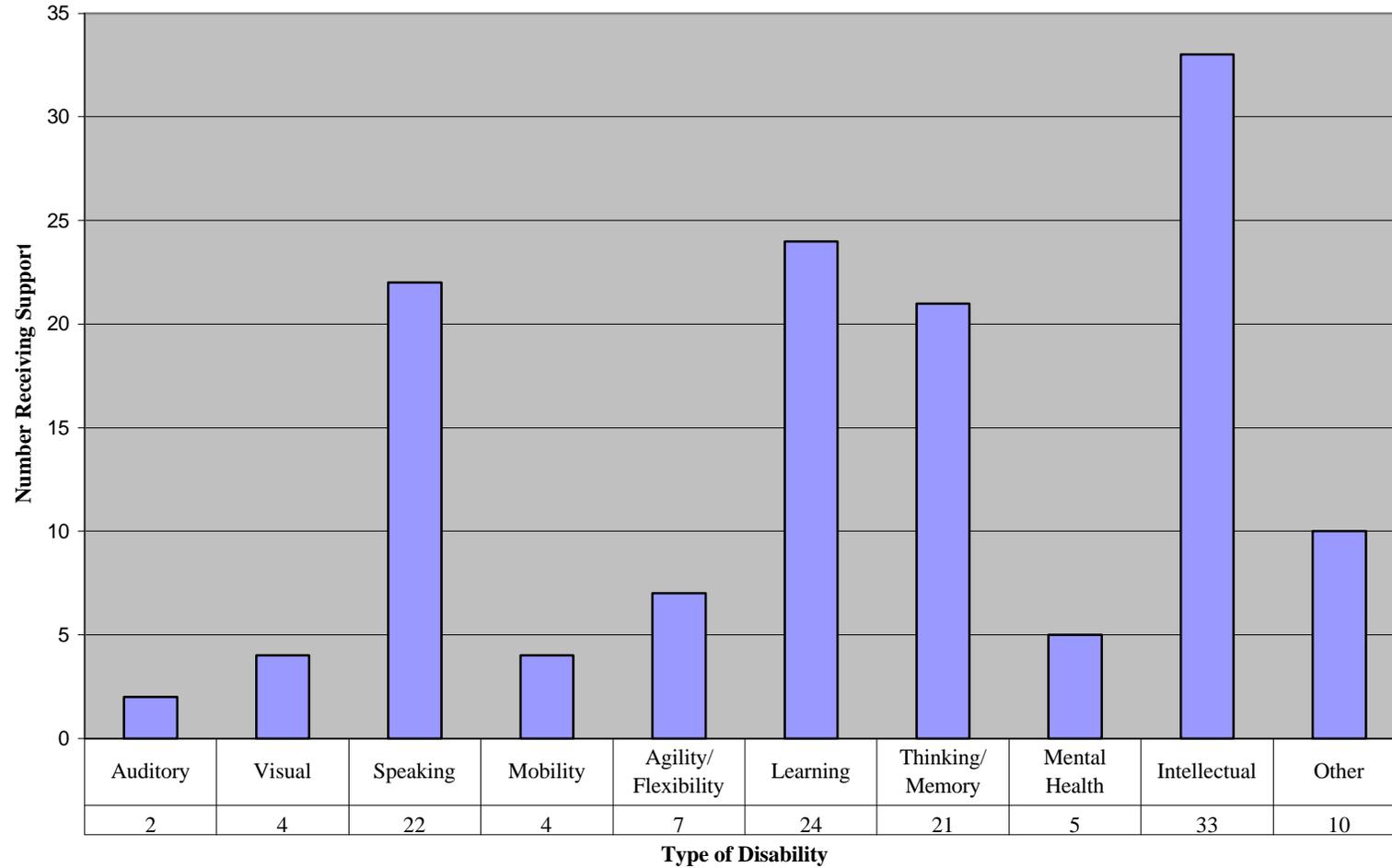
Table 2: Respondents currently working

Currently Working?	Frequency	Percent	Valid Percent
Yes	18	48.6	48.6
No	19	51.4	51.4
Total	37	100.0	100.0

Table 3: Respondents working and attending an educational institution, only working, only attending an educational institution, or neither working nor attending an educational institution

	Currently Working?		Total
	yes	no	
Currently in School?	yes	7	9
	no	11	27
Total	18	18	36

Table 4: Family members receiving support by type of disability*



*Family member receiving support could have more than one disability.

b. *Need for Supports*

- The **most needed supports** were: support for accessing and supporting involvement in community/recreation activities (87%); information and referral (81%); life/social skills development (78%). **Table 5** provides details on types of support needed.
- **Receipt of outside help** -- Of the 36 families whose family member with a disability was living at home, 18 (50%) received help from an outside organization or agency.
- Only 4 (10%) of the respondents received help from friends and neighbours; all of those who receive such help also received help from outside organizations or agencies.
- Of those respondents receiving help from an outside agency, 2 also received help from family members living outside the home.
- **33% of respondents with disabled family members living at home indicated that they received no help from friends, neighbours, or outside agencies.**
- **Need for accommodations** -- 84% of respondents need a modified/flexible work schedule in order to provide care.
- 78% reported a need for respite care.
- 65% reported a need for child care.
- 70% indicated they had difficulty participating in activities with other families because of a lack of special supports or equipment; 57% indicated difficulty because of lack of accessible transportation; 57% indicated difficulty because of “communication difficulties;” 38% indicated difficulty because they “were not wanted.”

c. *Engagement with Professional Services*

- 27% of respondents had not taken their family member with a disability to see a physician in the past 12 months.
- Almost half of families with a member who has difficulties with speech have not seen an audiologist or speech therapist in the past 12 months.
- 30% of respondents reported waiting a long time to get a doctor’s appointment “some of the time;” 24% reported long waiting times “most of the time” or “regularly.”

Table 5: Types of support needed by family members

Support needed for...	No. needing this support	Percent needing this support
Accessing and supporting involvement in community/ recreation activities	32	87%
Information and referral to needed supports and services	30	81%
Life/social skills development	29	78%
Accessing or using public transportation	25	68%
Accessing and participating in primary and secondary school	23	62%
General activities of daily living including attendant service, home care and homemaking assistance	22	60%
Individual planning and/or service coordination (case management, service brokerage, etc.)	19	51%
Medical care and rehabilitation (therapies, prosthetics, medical treatment, medication)	18	49%
Accessing and participating in adult education and vocational training	16	43%
Accessing and participating in early child development, including child care, pre-school programs	12	32%
Accessing and participating in post-secondary education	5	14%

d. Acceptance of Presence of Disability in the Family and Community

Respondents were asked how often they felt *accepted* by various members of their community (e.g., “Do you feel that your family is accepted by your parents?”). **Tables 6a through 6i** provide the results for these questions.

The results for this section are similar in nature to the survey questions which asked respondents (1) how often they felt *valued* by members of their community, and (2) how often they were treated differently by members of their community. The majority of respondents indicated that they were likely to be valued sometimes or most of the time, though – as indicated in the tables below – there are definitely some families who are facing exclusion, i.e. who do not feel they are accepted or valued by members of their extended family and community.

A majority of respondents indicated that they were often frustrated that people did not accept their family member with a disability as he/she is. However, this resulted in severe exclusion – the expectation that they should hide their family member – in only a minority of cases. Nevertheless, almost a quarter of respondents did indicate that they felt some pressure to hide a child with a disability.

Table 6a: Feelings of acceptance from parents/child’s grandparents

	Frequency	Percent	Valid Percent
Never	2	5.4	5.7
Hardly Ever	1	2.7	2.9
Some of the Time	6	16.2	17.1
Most of the Time	10	27.0	28.6
Regularly	16	43.2	45.7
Total	35	94.6	100.0
No response	2	5.4	

Table 6b: Feelings of acceptance from sisters and brothers

	Frequency	Percent	Valid Percent
Never	2	5.4	5.9
Hardly Ever	1	2.7	2.9
Some of the Time	6	16.2	17.6
Most of the Time	11	29.7	32.4
Regularly	14	37.8	41.2
Total	34	91.9	100.0
No response	3	8.1	

Table 6c: Feelings of acceptance from child's siblings

	Frequency	Percent	Valid Percent
Never	3	8.1	9.4
Hardly Ever	0	0.0	0.0
Some of the Time	7	18.9	21.9
Most of the Time	11	29.7	34.4
Regularly	11	29.7	34.4
Total	32	86.5	100.0
No response	5	13.5	

Table 6d: Feelings of acceptance from other relatives

	Frequency	Percent	Valid Percent
Never	3	8.1	8.6
Hardly Ever	1	2.7	2.9
Some of the Time	12	32.4	34.3
Most of the Time	8	21.6	22.9
Regularly	11	29.7	31.4
Total	35	94.6	100.0
No response	2	5.4	

Table 6e: Feelings of acceptance from family friends

	Frequency	Percent	Valid Percent
Never	4	10.8	11.4
Hardly Ever	1	2.7	2.9
Some of the Time	10	27.0	28.6
Most of the Time	7	18.9	20.0
Regularly	13	35.1	37.1
Total	35	94.6	100.0
No response	2	5.4	

Table 6f: Feelings of acceptance from neighbours

	Frequency	Percent	Valid Percent
Never	6	16.2	16.7
Hardly Ever	2	5.4	5.6
Some of the Time	12	32.4	33.3
Most of the Time	8	21.6	22.2
Regularly	8	21.6	22.2
Total	36	97.3	100.0
No response	1	2.7	

Table 6g: Feelings of acceptance from the community

	Frequency	Percent	Valid Percent
Never	5	13.5	13.9
Hardly Ever	0	0.0	0.0
Some of the Time	17	45.9	47.2
Most of the Time	5	13.5	13.9
Regularly	9	24.3	25.0
Total	36	97.3	100.0
No response	1	2.7	

Table 6h: Feelings of acceptance from doctor/support worker

	Frequency	Percent	Valid Percent
Never	0	0.0	0.0
Hardly Ever	0	0.0	0.0
Some of the Time	6	16.2	16.7
Most of the Time	13	35.1	36.1
Regularly	17	45.9	47.2
Total	36	97.3	100.0
No response	1	2.7	

Table 6i: Feelings of acceptance from other adults

	Frequency	Percent	Valid Percent
Never	3	8.1	8.8
Hardly Ever	3	8.1	8.8
Some of the Time	14	37.8	41.2
Most of the Time	11	29.7	32.4
Regularly	3	8.1	8.8
Total	34	91.9	100.0
No response	3	8.1	

e. Discussion of Survey Findings

Survey findings reflect mainly the experiences of the Chinese community, who were the overwhelming majority of respondents.

Those who completed the survey were likely to have at least some high school education or more; over a third had completed some kind of post-secondary education. They were likely to be married; the fact that fewer than half were employed is a possible sign that these respondents were full-time caregivers (unemployed female respondents were twice as numerous as unemployed males).

The overall picture of these families is positive: though we do not know their annual family incomes, they are able to support their child with an intellectual disability at home without resorting to shopping at food banks or sending their children to school or bed hungry.

Families most often lacked information and referral services – this corresponds with what was heard in focus groups about families not knowing what services and supports are available. Families also expressed a desire for their children to increase their participation in recreation and community activities; this desire was joined by a need for social skills education.

One third of families were completely self-sufficient: they reported receiving no outside help in caring for their family member with a disability. This lack extends to professional medical and rehabilitation services. Respondents nevertheless reported high levels of need for respite and child care, and – not surprisingly – reported that the family as a whole is negatively affected by unmet disability-related needs.

Compared to what was reported in the interviews and focus groups, one surprising result was that families did not report a broad lack of acceptance in the community. Members of the immediate family were likely to be supportive, though this is by no means always the case – several individuals reported that they never felt their family was accepted by the respondent’s parents and siblings (i.e. the child’s grandparents and aunts/uncles). Some even reported that their child with a disability was not accepted by his or her own siblings.

Feelings of acceptance were even less likely to be felt from the extended family, neighbours, and the community in general. Respondents reportedly feel accepted some of the time, indicating that there must often be times when they do not.

Nevertheless, the results – to the extent that they can be generally interpreted – indicate that there is a basis within the communities of those surveyed for a growth in acceptance and understanding. If families of children with disabilities are accepted, valued, and treated like other families some of the time, regularly, or even “hardly ever,” there is hope for growth of the valuing and acceptance that does exist.

As well, the responses of family members themselves – also evident in the focus groups – show that, in many cases, the bond of common experience and understanding that exists between parents of children with disabilities crosses ethnic lines.

B. The Toronto Somali Community

The Somali community in Toronto is no stranger to community organizing, nor to the establishment and use of organizations that provide services and supports to its members. There is a large number of organizations in the city started by, organized by, and composed of Somali individuals. Many of these are connected through the umbrella organization Midaynta, which specializes in settlement services for Somalis. Midaynta's member organizations include the following:

- Somali Canadian Association of Etobicoke
- Somali Canadian Counselling Association of Ontario
- Somali Family and Child Skills Development Services
- Somaliland Women's Organization
- Somali Community Centre of Etobicoke
- Ogaden Somali Community Association of Ontario
- Somali Canadian Community of Ontario
- Somali Immigrant Aid Organization
- Somaliland Canadian Society of Metro Toronto
- Somali Banadir Association
- North York Somali Immigrant & Culture Support
- Inter-Riverine Somali Relief Association Supporting Group
- Somali Southern Community Association of Ontario
- Somali Canadian Integration Society

The capacity of these organizations to organize around disability was demonstrated on April 3, 2004 at the First Somali Mental Health Conference, held at Etobicoke City Hall. The conference was attended by over 100 individuals, and featured talks by medical practitioners, social workers, and – notably – the sister of a man with schizophrenia. This woman was seen as very courageous by those in attendance, as it has been the tendency in the community to hide the existence of mental illness rather than speak out or look for help.

The conference also brought attention to the growing numbers of Somali professionals who have succeeded in acquiring licenses to practice medicine and psychiatry in North America. These professionals could act as valuable access points into the community, as well as important conduits to spread information about the differences between mental health problems and intellectual disability – a distinction that needs to be made if issues related to intellectual disability are to be addressed in the community.

1. Literature Review

Unofficial estimates of the Somali population in Toronto vary widely – from forty to fifty thousand (Immen, 2000; Elmi, 1999; McGown, 1999) to 75,000 (Israelite et. al., 1999), to 200,000 (O'Reilly, 2003). Statistics Canada puts the Somali population in Toronto in 2001 at 17,380 (mixed Somali and other origin) and 16,105 (Somali only origin),² which is the lowest

² Source: Statistics Canada, 2001 Canadian Census tabulations, Table 97F0010XCB01001.

estimate in the literature reviewed for the current research. This group's major location is in Etobicoke at Dixon Road, east of Pearson Airport, with smaller communities in Regent Park in Toronto's downtown centre/east, and in Scarborough.

It has been said that Somalis share a common language, heritage and (Islamic) faith (BBC London, 2003), and as such would appear to be a relatively homogeneous group. However, members of the group are separated by membership in different tribes, or clans (Silveira & Allebeck, 2001), and the Somali people have been described as highly heterogeneous (Griffiths, 2000, 282), with differences between those who have emigrated from the north, the south, and the central and coastal regions of Somalia and Somaliland. There may also be language differences between Somalis fluent in the Af Maay (also called Maay-Maay) versus the Af Maxaa dialect. The Virginia Refugee and Immigrant Health Program has produced a bulletin that reports "while there are similarities between the written forms of Af Maay and Af Maxaa, the spoken forms are different enough to be unintelligible." Van Lehman & Eno (d/u) write:

Since independence in 1960, Somali governments have promoted the false notion that Somalia is a homogeneous nation, a claim reinforced by some Somali nomadic scholars and non-Somalis as well. The myth of homogeneity falsely represents Somalia's dominant nomadic culture and tradition as the nation's only culture and tradition... some experts estimate that up to one-third of all Somalis are minorities, representing a variety of cultures, languages, and interpretations of the dominant Sunni Islamic religion.³

Somali communities of newcomers are characterized by high rates of single parent (i.e. single mother) families, owing to the high ratio of men versus women killed during the civil war, and the tendency of men to remain in Somalia while their families moved to refugee camps and then on to Canada. The transition for Somali women from caregivers in a heavily patriarchal society to independent heads of families adds to the stress of dislocation and multiple-trip migration (Israelite et. al., 1999; Osaki, 1997).

a. *Engagement with Service Agencies and Organizations*

Israelite et. al. (1999) report a number of sources of long-term discrimination that Somalis face upon relocation to Canada. These include obvious discrimination from landlords and potential employers, to structural discrimination entrenched in Canadian immigration legislation. For example, due to the widespread lack of citizenship documentation from Somalia, and Canadian government regulations, refugees must wait at least five years to achieve landed immigrant status. During this time they are unable to leave the country with a guarantee of re-entry; they are unable to sponsor family members to come to Canada; they are only allowed access to temporary work permits; and they are often ineligible for employment programs offered through Human Resources Development Canada. The authors characterize this population as "amongst the most disadvantaged racial and ethnic minorities in Canada" (5), and discrimination is seen as a major reason for the limitation of personal interactions of Somalis to within their own community.

³ In contrast to this characterization, the reader is referred to the quote in section IV which discusses the Toronto Somali community's successes in overcoming differences in order to create a more homogenous Somali identity.

Israelite et. al. describe a need for higher levels of privacy within this community when compared to other Canadians. In addition, “because of the oral tradition in Somalia, many of the women [are] unaccustomed... to the culture of paper that characterizes Canadian and other Western bureaucracies” (20). This combination of factors necessitates a very high degree of effort to become acclimatized to the Canadian system.

Opoku-Dapaah (1995, 61) adds to this characterization when he writes, “Somalis tend to limit their social activities to interaction with other Somalis and within their immediate geographic confines... Those with university education tend to participate in activities outside their neighbourhood.” Silveira & Allebeck have also commented on the failure of (now retired) Somali seamen to create a large social and/or merchant community consistent with the length of their residency in the British Isles.

Elmi (1999, 9) reports that

Significant numbers of Somalis ignore the existence of certain services. Such services were not available back home with the result that they are generally quite underutilized here. Even when people do know of the existence of specific services, they may not know how and where to get them. This induces many to simply desist from seeking help. Often people tend to drop in without appointments expecting to obtain service immediately. Language barriers and the formality connected with service delivery discourages some people from using non-emergency services.

As a group with a similar history to that found in Toronto, the Somali population in the United Kingdom, and particularly London, could serve as a valuable starting point for learning about service provision to this population. It has the advantage of a longer history: London is home to British-born Somalis (descendants of Somali seamen employed by the British navy and commercial fleets) as well as those displaced by the recent civil war. A number of service agencies in Britain have grown up around these groups.

One of these service providers is Mind (www.mind.org.uk), which professes to be “the leading mental health charity in England and Wales.” Their service goals appear similar to those of Community Living Toronto, and include “challenging discrimination and promoting inclusion,” and “inspiring the development of quality services which reflect expressed need and diversity” (Mind, 2003). The organization has established the *Diverse Minds* network to respond to the service needs and concerns of Black and other ethnic minority communities in Britain and Wales. The website provides a few clues as to why minority communities might be wary about making contact with service agencies:

- One survey showed that, for people from minority ethnic communities who needed secure psychiatric care, 85 per cent were placed in a psychiatric hospital or ward;
- People from ethnic minority communities are likely to be given physical coercive treatments like ECT or drugs rather than talking treatments in 95 per cent of cases;
- 74 per cent of clients are given little or no choice of treatment.

Diverse Minds has a number of strategies in place to address these problems, including a quarterly magazine, a website specific to ethnic minority mental health issues, and a Liaison Officer who has “continuous” contact with the service provider and the communities in question.

BBC London reports that this is the only health service group in the city that works specifically with the Somali community. However, the news service also lists the East London Somali Consortium, the Lambeth Somali Community Association (immigration advice and legal aid), the Somali Caring and Education Association, and others.

The Somali community in the United Kingdom, along with the Bengali community, has been characterized by Bell et. al. (1999) as difficult for health services to reach in comparison to other ethnic minority groups such as Urdu and Gujarati speakers. He cites several reasons for this difficulty:

- There is little translated (i.e. Somali language) literature in the community;
- In a study of breast cancer screening, “Only one of the 32 Somali women invited for screening attended after receiving her invitation. A Somali community link worker visited those who did not attend and reported that they were unable to read in either Somali or English. This applied, to a great extent, to other family members. Somali has only been a written language for thirty years; prior to this the language was exclusively oral. It was only in 1975 that the Somali language, in a written form, became widely disseminated... As women invited for breast screening are at least 50 years of age, they would have had little opportunity to learn to read their own language. Of the 31 Somali women visited by the link worker, 7 (23%) preferred not to attend and opted out of screening and 12 (41%) women subsequently attended” (Bell et. al., 1999).
- Bell et. al. found that Somali women and their families had respect for their doctor. This could be generalized to doctors in general, and may indicate an increased response when support services are endorsed by medical professionals.
- “Our research illustrated that the Somali community constitutes a special category with unique problems; they require individual attention and encouragement from someone they can understand and trust. The involvement and active participation of well-integrated members of ethnic communities would be beneficial in planning strategies and implementing interventions” (Bell et. al., 1999).
- “Disability was low among old Somalis, although ideas that disability constituted moral weakness or lack of faith in God may have led to under-reporting according to our interpreter” (Silveira & Ebrahim, 1998, 381). The actual results – ninety-three percent of Somali research participants over age 70 reported no (physical) disability in activities of daily living – certainly supports the hypothesis that illness and disability are taboo in this culture. Even participants with chronic health problems indicated that they did not have a disability.
- “A central theme was the perception that health and death are all divine matters ultimately determined by Allah. Religious explanations of disability that invoked fate and chance were not exclusive though – health outcomes and longevity were also seen to be contingent upon behaviour and genetic make-up (among the more educated)” (Silveira & Allebeck, 2001, 314).

There does not seem to be a generalized unwillingness to use health and social services, at least among older Somali men in the Silveira & Allebeck (2001) study. Healthier subjects were likely to have consulted a doctor in the recent past, and those with better capacity in the English language were more likely to report satisfaction with such consultations.

Though their findings may be only partially generalizable to the general Somali population, Silveira & Allebeck (2001) found a correlation between religiosity and the tendency to accept one's life problems. Religious faith may prevent "disclosure of symptoms of anxiety and depression among people who perceived the subject to be prohibited, a sign of lack of faith in God or moral weakness" (316). Giving in to and/or accepting disability may be prevented by a fear of divine punishment for this weakness. Discomfort with the subject was shown by one man who said, "...someone who is not strong enough and his belief is weak, who could not cope with these difficulties. I don't think I am this sort of person... I can't talk about it... I was not expecting this sort of questions, I thought it would be something else" (quoted in Silveira & Allebeck, 2001, 317).

Silveira & Allebeck also raise the confound of a group that is considered/considers itself to be self-sufficient and therefore is characterized by low service engagement, but actually requires significant involvement from services of the host country. Insularity is predictably unhealthy for a group that is relatively new to the country, that may be experiencing individual and/or group trauma from civil war and forced migration, that has low levels of literacy in both the home and host country languages, and that is likely to encounter the discrimination in employment that is an issue for many Black communities in the Toronto area (see, for example, Canadian Immigration Hotline, 1993; CBC News, 2003; Carey, d/u; Wilkes, d/u).

Unfortunately, Silveira & Allebeck's studies were only of older Somali men who had not been displaced by the civil war. A recent study in Toronto, while not examining attitudes per se, looked at prevalence of mental health problems among more recent refugees and immigrants in Toronto. Elmi (1999, 2) writes that "the occurrence of suicide and major mental health disorders within Toronto's Somali Community gave concern that mental illness was on the rise and was causing severe distress for families and individuals." This opinion was borne out in interviews conducted for the present research.

Griffiths (2000) undertook a study of Somali and Kurdish refugees in London that illustrated the difference between two types of communities – those that are able to establish a public face and "communal voice" with which to interact with out-group cultures (including government bureaucracies and service groups) and those that are not. While the Kurdish community (which seems to share many attributes of Tamil communities) was able to do this, the Somali community is said to be characterized by "invisibility and the apparent absence of any organized political or social presence" (284). He later paraphrased this for emphasis: "In the current research, negligible and fragmentary community organization, social marginalization and the absence of a coherent political project stand out as the defining features for the Somalis in East London" (294). As one Somali man said, "When they came from Somalia they witnessed a lot of fighting... dead people. Always you know how to fight. You don't know how to sit down and talk to each other... So when they see any community organization, they swear that they can get something... They don't understand that it is a voluntary organization" (288).

This combination – fragmentation and lack of organization with poor knowledge of the social environment of the adopted country – could prevent individual Somalis from accessing needed services even if they had the desire. This situation appears to be analogous with the situation of persons with intellectual disabilities before parent organizations began to be formed, or with Afro-Americans in the southern states before the formation of the nucleus of the civil rights movement. This points to the need for communities to organize before they can begin to interact with existing social groups and services. The combination of lack of English-language skills, mistrust of out-groups, fears of discrimination, and lack of basic knowledge of service systems raises significant barriers to interaction with agencies like Community Living Toronto.

b. Somali Beliefs and Attitudinal Tendencies Towards Disability

While information about Somali attitudes and beliefs about intellectual disability is almost non-existent, there is evidence that Somali health practices are informed at least partly by traditional beliefs about causation and healing of illness and disability; medical professionals may not be consulted unless traditional methods are found wanting. Elmi (1999) and Silveira & Allebeck (2001) have written of the belief that “illness and healing occur only by the will of God (Allah)” (Elmi, 1999, 5). Suffering with dignity may be interpreted as a means of having one’s sins forgiven by God – “Disease is accepted and the condition is to be borne with dignity.” Elmi also writes that “culturally a person is either sick or in good health,” with no middle ground between the two.

In addition to beliefs about the role of God in physical and mental well-being, Somalis may also see curses by other people or spirits as causes of ill health: “Very common among interpersonal diseases is the so-called ‘il’ (evil eye)... diseases can also be caused by witchcraft. A majority of Somalis also believe that some diseases are caused by spirits (‘jinni’ or ‘jin’)” (Elmi, 5).

Somalis have been known to practice traditional medicine and use quasi-medical approaches. These practices (particular reference is made here to female circumcision) could serve to isolate the community from service providers when the practices are understood to be taboo in the adopted culture. Under this umbrella are “cures” involving readings from the Qu’ran, use of herbs, applying a heated nail or other piece of metal to a wounded or infected area (i.e. cauterization – fire and disease may be believed unable to coexist), “scarification, fumigation and wearing of amulets” (Elmi, 1999, 5).

2. Somali Community Interviews and Focus Groups

Proceedings with the Somali community were by far the most difficult to coordinate. While individuals within the community were extremely welcoming and helpful to representatives of Community Living Toronto and The Roeher Institute, little luck was experienced in enticing individuals or employees of service organizations to come to focus groups.

We proceeded to undertake a series of interviews with three mothers and one father of children with disabilities. The interview group assembled at the office of a Toronto Somali service organization. Participants arrived at various, and consecutive, times throughout the morning.

More than one observer has noted that Somali conceptions of time and keeping appointments may not always be consistent with Western notions of punctuality.

We asked participants a list of prepared questions. A Somali employee (employed through the Developmental Services Worker Program at Centennial College) translated the questions, and then the responses of the first participant, Amina.⁴

Amina is the single mother of five children. She is not currently employed, and her family receives Social Assistance. One of her daughters is ten years old, and from her description appears to have Cerebral Palsy. The family lives in a small apartment, and her daughter “screams a lot” according to her mother.

Amina accesses supports through a large Toronto area children’s centre, and had never heard of Community Living Toronto or accessed their services. Her daughter receives intra-muscular botulinum toxin type A (i.e. Botox) injections, which gives her greater freedom of movement. She is also able to access speech therapy, in the context of a special class in her school, where she has two teachers who are described as ‘very supportive.’

Amina reported a need for support to take her daughter outside and to recreational programs, as well as a need for respite services to give her a break from providing care. She expressed a desire for her daughter to be in a regular class, but does not know how to go about accomplishing this goal – the language barrier is a problem here. She asked the group how she could access advocacy support in this area.

While her experiences with the children’s centre have been good, Amina also spoke of times when a government agency promised to provide services, but no one showed up to her home. As well, a social worker gave her a phone number to call and promised a form to fill out but never sent the form. She does not know who they were or what agency they worked for.

When asked about the availability of informal supports from friends, family and neighbours, Amina reported that friends will give her money for a taxi, or will provide car rides to get to appointments, but are unlikely to share caregiving duties with her.

Asad was the second parent interviewed. He is the father of an eight year old son who has Down Syndrome. They are having “many problems” coping with this. He has contacted a government office, through which the Ministry of Community and Social Services provides him with a few hundred dollars per month.

His son attends a middle school on Toronto’s east side. In the spring of 2003, the school had seven special education program classes (Toronto District School Board, 2003), but there was some confusion as to whether Asad’s son was in a special class either part or full time. At the time of the interview, the family had been in the country for 13 months and, though a nurse visits the home to provide speech therapy, reportedly not getting the amount of support needed. Asad’s son is “sick a lot of the time,” and spends time in the hospital on a regular basis. He has syndrome-related medical complications, and is often unable to sleep through the night.

⁴ All names have been changed to maintain the anonymity of participants.

Asad's main concern seemed to be the safety of his son, who does not understand the concept of danger, including heights. This is a problem, considering the family lives on the sixth floor of a rent-subsidized building, and Asad's requests to move to a lower floor have been denied by the building management. His son will eat anything regardless of safety or edibility. There are also problems with his son's staying put on the school bus, and he is often picked on by other children.

When a CLT representative asked Asad about the school, he said that the principal is nice, but Asad doesn't want to complain and doesn't know what kind of supports are available to him.

Both Amina and Asad have been helped by one of the service organizations in the Somali community.

Habiba is the mother of a sixteen year old son with an intellectual disability. While he does attend school, his literacy and numeracy skills are very low, and he has few friends in the neighbourhood where they live. Habiba stated that he needs to have more opportunities to participate in activities and recreation, and to make friends. He could also benefit from tutoring, as well as someone to take him outside and to programs, sports and other activities.

Habiba has seven children, of whom the sixteen year old is the eldest. While he is most often alone and isolated, he is working through a co-op program in school, and also participates in volunteer employment. He needs continual support, and it was through the school that they found out about the monthly allowance of \$225 provided by the Ministry of Community and Social Services. Habiba also filled out several other forms for MCSS, but hasn't heard anything since handing them in – apparently this is not an isolated event.

Iman is a single mother with six children, three of whom (three, six and fifteen years of age) have hearing impairments. She had been having trouble getting her fifteen year old daughter to school, as the bus no longer picks her up, and the school does not seem to be helping in an advocacy context. The school is integrated, with both students who do and do not have hearing impairments. Her daughter is reportedly lagging behind her peers in school.

Iman spoke of a need for tutoring, as she herself left school in grade 8 and does not feel capable of providing adequate help. She has been unable to pay for services – apparently this is a widespread problem for families and individuals needing hearing services – and is on a waiting list for services from a private service organization. A service organization sent a for-fee service provider who she could not afford to pay for.

3. *Interviews with Somali Service Providers (1)*

While we had planned a focus group with a number of agencies providing services and supports to the Toronto Somali community, we again had difficulty attracting a significant number of participants. The planned focus group instead took the form of a group interview, during which we discussed a number of issues with a few very active members of the Somali community.

a. *Community Engagement with Service Agencies and Organizations*

When speaking of individual Somalis' interactions with non-Somali service agencies, the touchy subject of government avoidance is likely to be raised, which is not only an issue among the Somali community. Illegal immigrants, people in the process of claiming refugee status, and people receiving Social Assistance may wish to stay as far below the radar as possible. This can combine with a learned tendency of mistrust of government that has grown out of experiences with corrupt and manipulative governments in the homeland. Somalia has been without government for 14 years, and consideration must be taken of the Somali understanding of what government is, and what it does. "The Somali immigrants face many obstacles in accessing services in the Canadian system because Somalis have experienced a fear of Government, Government agencies and a highly structured social system" (Somali Immigrant Aid Association, d/u).

The interviewees also noted that there may also be confusion as to how service agencies are connected to government. If there is a perception that information travels, so to speak, some individuals may be unlikely to approach an unknown organization offering services. Some agencies interviewed in the research explicitly tell potential clients that no information they provide will be passed on to government.

b. *Perceptions of Intellectual Disability*

When speaking about intellectual disability with a person of Somali background, it almost without fail becomes quickly evident that one of this community's most pressing problems is the presence of post-traumatic stress, depression and anxiety-related mental health problems among a large number of recent immigrants. The evidence of this is the nearly universal tendency to confuse intellectual disability with mental health issues.

The Somali service providers who participated in the research often started our discussions very interested in what the project was about. Five minutes into the conversation, it would typically become clear that we were talking about different things: while the Institute and CLT representatives were speaking of intellectual disability, representatives of the Somali community were speaking of mental health.

Once this realization was made, interviewees would either ask what was meant by the term "intellectual disability," or would say something to the effect of "hmmm... yes, I think I know one person like that," or "yes, there used to be someone like that living near to me, but I do not know if they are still there."

The conversation was very helpful once everyone was on the same page. For example, it was said that a child with a disability is considered "sick," and there is little discrimination between types of sickness/illness/disability etc. One of the interviewees is a doctor trained in Romania (common among Somali professionals, as is training in Italy) who remarked that a person experiencing symptoms of post-traumatic stress, or depression, or anxiety, may say to their doctor, "I am feeling bad all over." There may often be little understanding that problems can stem from the brain rather than the body.

This situation is exacerbated by the stigma placed on problems “above the neck.” A colloquial term often used to describe such problems is “waali,” – loosely translated as “crazy” – and, as is the case in the English language, there are many other similar terms that have similar meanings. Such terms are applied indiscriminately to people with intellectual disabilities and mental health problems.

The interviewees also talked of a culture of naming people – “Mr One-eye,” “Ms. One-leg,” etc. While this naming is not necessarily meant as a means of denigration (it is more likely to be applied in humour), a person’s most obvious physical or other characteristic is likely to become their ‘tag.’ Further research would be necessary to understand how this naming relates to normative features of the culture, but it must be assumed that notations of difference serve to denote a person’s distance from the ideal.

Intellectual disability and mental health problems can be distinguished by the fact that the latter are often transitory. The hope for a cure for mental illness separates the two conditions. The fact that mental health issues can be attributed to civil war and displacement also bodes well for the possibility of overcoming the stigma associated with that condition. Intellectual disability is much less well understood, less widespread, and therefore less likely to escape stigma associated with conditions “above the neck.”

4. *Interviews with Somali Service Providers (2)*

In separate interviews with representatives of two Somali-run service agencies, similar themes came to the fore as were heard in the interviews discussed above. The first theme was ongoing confusion about the difference between intellectual disability and other “above the neck” issues. For the first five minutes of the second interview, the group of four (two interviewers and two interviewees) discussed the fact that many Somali children and youth were being placed in special education classes, though “there is nothing wrong with them.” This is reportedly happening often, with children and youth more recently arrived in the country reportedly more likely to be placed in separate classes.

When the group realized that we were not talking about individuals with intellectual disabilities, we asked the interviewees about children and youth who had some kind of learning or intellectual disability. There was a pause, and an admission that the agency knew of very few such individuals and/or families. It was also assumed that, given the recent arrival of the Somali community in Toronto, such individuals were likely to have been turned away at the border, and there has not necessarily been a lot of time during which Canadian-born Somali children with disabilities could have been born.⁵

It was also suggested that individuals and families would be more likely to address their concerns and needs at a hospital rather than a Somali service agency that is better known for its immigration and naturalization services. There may also be fear that a Somali agency would suffer from the same prejudices and taboos of the community at large.

⁵ In contradiction to this belief, we recently heard that there are approximately/at least 60 Somali families who have children with intellectual disabilities in the GTA. This figure is yet to be confirmed.

When asked how the Somali community is likely to perceive intellectual disability, the widespread stigma attached to illness, weakness and difference was raised. It seems that there is even stigma associated with tuberculosis, or in fact any illness not associated with a civil war wound, which would be displayed with pride. As noted above, intellectual disability would be placed in this category of “illness.” It was said that there are “too many taboos.”

Perhaps the most prescient phrase used by an interviewee to pinpoint the issues facing the Somali community in Canada – whose members deal with recent upheaval, separation from family members, loss of home and belongings, moving to a different culture and climate, problems with employment discrimination, discrimination in general, and widespread post-traumatic stress and other mental health issues – was that “When there are fifty priorities, if you focus on all of them, you do nothing.”

C. The Toronto Tamil Community

Ethnic Sri Lankan Tamils are – like Somalis in Toronto – by no means new to engaging with established organizations and service/support providers. Tamils have been notable partners in hospital-based programs both in Scarborough (i.e. the Ethno-racial Seniors’ Project) and at Mount Sinai on University Avenue (i.e. the Assertive Community Treatment [ACT] Team).

In addition to community groups such as the Canadian Tamil Congress, the Tamil Eelam Society, Canadian Tamil Women’s Community Services, and the Toronto Tamil Seniors’ Organization, the Tamil community has a vibrant online presence at www.tamileelamnews.com and www.tamilcanadian.com.

1. *Literature Review*

Estimates of the number of Tamils in Toronto vary widely. Radio Asia has put the population at over 130,000 (CRTC 1998); another source estimated about 73,000 in 1994 (Aruliah, d/u). Information from Statistics Canada places the 2001 Tamil population in Toronto at 33,145 (mixed Tamil and other origin) and 23,170 (Tamil only origin). Major concentrations are located in Scarborough, north Mississauga, and pockets in the downtown core.⁶

a. *Engagement with Service Agencies and Organizations*

According to a report by Health Canada’s (2003) Health Care Network, there is often a support shock for Tamils who, in the home country, had large extended families to provide support. Once in Canada, individuals and families can become isolated, and may be “afraid to take their children to the doctor or to talk about their loneliness.” The use of outreach and language-specific booklets that use illustrations and simple language have helped to bring people into contact with health services.

At the same time, this population seems to have translated its collective nature to communities in Canada. Judging from the proliferation of websites hosted by members of the Toronto and Scarborough Tamil communities, this population is no stranger to community organization and provision of services to in-group members. The Tamil Eelam Society of Canada (TESOC), for example, was founded in 1978, has four offices in the Toronto area, and is led by a 12-member Board of Directors. The Society receives funding from Citizenship and Immigration Canada as well as the City of Toronto. Their major projects are directed at employment, language instruction for new Tamil Canadians, settlement and adaptation services. They also provide “voluntary services” and counselling, but disability supports, and people with disabilities, do not seem to be on their radar as a distinct categorization.

The Scarborough Hospital also seems to be responsive to the needs of the Tamil community, as evidenced by their Gestational Diabetes Program for Tamil Women. This program is administered by the Tamil Eelam Society, with support from the Self Help Resource Centre, the Canadian Diabetes Association and the Diabetes Education Community Network of East

⁶ Source: Statistics Canada, 2001 Canadian Census tabulations, table 97F0010XCB01001; for population clusters see www.city.toronto.on.ca/ourcity/images/profile2_map4.gif.

Toronto (Canada News Wire, 2003). Also of interest is the Tamil Caregiver Project at the Providence Health Centre in East Toronto.⁷

The Scarborough Tamil population, through the Canadian Tamil Congress, was involved in community health forum debates on the Romanow Commission on the Future of Health Care, with emphasis on access and equity to services and the certifying requirements for foreign-trained medical professionals. One doctor stated that the two main barriers to the Tamil community's use of health services are lack of awareness of what is available, and lack of English-language skills in health encounters. There are not enough Tamil-speaking service providers in the areas of diet and nutrition for diabetics (which seems to be a major health issue for this population), prenatal classes, paramedical services, social workers, physiotherapists, nurses and psychologists. This doctor also stressed the need to inform the community about preventative rather than reactive health practice (TamilCanadian.com, 2002).

Other discussions at the community health forum revolved around women's physical and mental health. There was also discussion of the need to promote the inclusion of Tamil seniors to prevent elderly depression. Presenters spoke against the "devaluing of their roles in Canada," and of facilitating discussion between seniors and the greater community. These sentiments, and those related to mental health, show an openness to the inclusion of people traditionally pushed to the periphery of communities.

A recent study in which three out of four of the researchers are Toronto-based (Meana et. al., 2001) looked at breast cancer screening behaviours in Tamil immigrant women over age 50. While this seems only weakly related to studies of persons with disabilities, it may provide insight into the relationship between Tamil groups and Canadian health and social services.

The authors of the study found that study participants who had higher levels of education, had been in the country longer, and who were more acculturated (as measured by the Suinn-Lew Asian Self-identity Acculturation Scale) were more likely than other Tamil women to have had at least one mammogram. However, the most salient factor in the use of mammography services "was in the perception of barriers to breast self-examination and, especially, to mammography... the barriers identified in this study were: the procedure engendering worry about breast cancer, the embarrassing nature of the test, the time-consuming aspect of mammography, fear of pain during the test, and cost. With the exception of cost, which is considered an access barrier, these barriers are psychological in nature..." (Meana et. al., 2001, 186).

b. Tamil Beliefs and Attitudinal Tendencies Towards Disability

There are few studies or discussions of perceptions of disability in Tamil culture. The only specific study found during the current research is Bakheit & Shanmugalingam (1997), which looked at a predominantly Tamil rural Indian community. The study found that, while 82% of respondents "showed a positive attitude toward people with a disability" (329), older respondents were less likely to be positive. By "disability" the authors are referring to physical disabilities, mostly "due to old polio, bone fractures or limb amputations. A few patients had spinal injuries" (331). Given that this study is one of the few to analyze perceptions of any kind of disability, it is

⁷ For information, see http://www.providence.on.ca/programs_ccentre_tamil.asp.

very difficult to know how Tamil populations approach people with intellectual disabilities. The authors do note that less visible forms of impairment are accepted more readily than more obvious forms such as leprosy.

2. *Tamil Community Focus Group*

A focus group with non-professional Tamil individuals (e.g. persons with disabilities, family members, representatives of voluntary organizations) was held on March 24, 2004 at the Scarborough offices of Community Living Toronto. Approximately 20 individuals attended, and were joined by several CLT employees as well as the Roeher Institute interviewer.

After a CLT representative welcomed everyone to the meeting, participants were asked to introduce themselves and tell the group about why they were attending – it was presumed that they would tell us about their disability, or about their children who have disabilities. Countering expectations, as we went around the table it became clear that the concept “person with a disability” was being understood quite loosely.

Participants introduced us to their diabetes and high blood pressure problems, cataracts, asthma, stress, lymphoma in remission, mild physical problems, and mental health issues. One woman experiences bipolar depression, and one man has two adult children with mental health problems. Also present was a woman who has a daughter who is deaf, unable to speak, and whose son-in-law is also deaf (the couple has two hearing children). Two men are either completely blind or have low vision. Another woman has a son who is 5 years old and has a heart defect (from birth) and medical complications. Though it was unclear whether or not he had an intellectual disability, he is in a special language program in school. Also present was the father of three children who do not have disabilities, though his wife has mental health problems. There was only one woman who was clearly the mother of a child with a disability (a son with Autism). The group was joined ten minutes into the discussion by a married couple who were both visually impaired.

a. *Community Engagement with Service Agencies and Organizations*

One participant, in response to a question about problems with social services, said that there is not enough information about the services and supports that are available. With regard to his own children, it took a great deal of time to diagnose their problems. He added that, where people are able to get information about and access services, they may often be turned away; this had been his experience with a particular hospital in Scarborough. Alternatively, he noted that service providers may require more information and documentation than people may actually possess.

It was said that the only hospital in Scarborough with an assistive devices program closed, and therefore the link to assistive aids was ended.

The group then went into a lengthy discussion about one participant’s problems with the Toronto Transit Commission, particularly Wheeltrans – they were judged ineligible for service at first, and again on appeal. A representative of a voluntary organization said that it was important that

they learn what they were supposed to say – to “say the right words” – in order to get access to Wheeltrans.

This did not seem by any means to be an issue of racial discrimination, but there was a perception that whites and other established Canadians would have known what to say in order to get the service regardless of whether they needed it or not. There was clearly a need for information about self-determination and independence for the couple. The same overprotectiveness and reliance on outside sources was evident in the case of a woman providing care to a daughter and son-in-law, who seemed to dismiss out-of-hand the option that her offspring could take better care of themselves. From the perspective of the Canadian independent living movement, these adults with sensory disabilities could have been learning more independent living skills.

It was pointed out that information from within the Tamil community is very important for referral to services, but the community itself does not necessarily provide connections to professional mainstream services (e.g. Surrey Place Centre, Bloorview MacMillan Children’s Centre), which are widely used.

The mother whose son has Autism told us she has succeeded in finding a general practitioner that she is happy with, though she expressed a need for respite care and/or free time for herself. She is not receiving help from any family or friends, though she does have connections to several medical/rehabilitative agencies in the Toronto area. Her husband also provides care for their children on a regular basis.

3. *Tamil Service Provider Focus Group*

A focus group was held with representatives of organizations that provide services to or perform research within the Tamil community. It was held at the Scarborough offices of Community Living Toronto on March 23, 2004. Approximately 15 individuals attended.

As introduction, the group was told the objectives of the focus group. It was noted that the researchers wanted to hear about how Tamil persons with intellectual disabilities were faring in Toronto communities. To get the group talking, the group leader asked for some general perceptions/input on the topic.

a. *Community Engagement with Service Agencies and Organizations*

The first person to speak said that her organization received most referrals from doctors, schools, daycare centres, and friends of families of children with intellectual disabilities. She had been told/had found that Tamil families in this situation were often not ready to integrate with their own community, and therefore were more comfortable going outside the community to non-Tamil/mainstream service providers. Rather than deal with the limitations that were seen as inherent to Tamil understandings of intellectual disability, some Tamils found more acceptance and aid from people who shared knowledge of intellectual disability rather than those who shared ethnicity.

Two focus group participants reported that there currently are connections being made within the Tamil community. Their organization has compiled a database of about 150 persons with disabilities, about 10 of whom have intellectual disabilities. Though they have had trouble getting government funding and their scope of services is small, they succeed in making contacts mostly through networking and word of mouth. Shortage of funds allows them to work only 10-15 hours per week, and they are unable to fulfill their mandate. Addressing the issue of services provided by mainstream service providers, they pointed to the problem of language barriers, as well as a lack of knowledge in the community about services and transportation. They stated that families are generally the main source of support for Tamils with disabilities, and opportunities for learning about alternative forms of care are limited.

The point was made that there is not necessarily a capacity for Tamil service organizations to reach all individuals and families who need help.

One participant noted that ethnic families stay on caseloads the longest. She attributed this to the need for ESL instruction, a lack of clarity about services, and the fact that it is these families who need mainstream services the most. While white families are more likely to find community supports, ethnic families may depend more on professional services.

It was noted that the Family Services Association (FSA) has targeted intellectual disability in the Tamil community through outreach, awareness and capacity building. It is worth noting that the FSA also has an office at the Rexdale Community Health Centre, in an area with a large Somali population.

When a participant remarked that there is a need, in the case of recent immigrants, for both parents to be in the workforce, the group leader asked about the community resources that are available, i.e. who takes care of children while parents are at work? The group responded that grandparents and neighbours often care for children.

This answer generated quite a bit of discussion among the group, and it was said that there are a lot of services, but again that people don't necessarily come out to access them. It was also stated that there is little emphasis on "caring for the caregiver." There are pockets of support in the community, but it is not necessarily widespread – there is still shame. For example, a newborn with a disability may not be spoken of or celebrated.

b. Perceptions of Intellectual Disability

One participant stated that Tamil families may be overprotective and may not push family members into the community – many persons with disabilities are never seen at social gatherings. However, there are people in the community who will go into the home and provide families with needed help.

A researcher involved in a large scale project that has interviewed a large number of Tamils in Toronto, stated that there is still a lot of denial and stereotyping in the Tamil community. Families are likely to deny the presence of intellectual disability, or to not recognize it when it exists. Families may be patronizing and protective of people who are intellectually disabled. He

also pointed to a lack of awareness about services among the community, and the fact that the system caters mainly to English speakers.

There is a contradiction within the community revolving around the desire for all children to have advanced academic skills – it may be difficult for families to accept that this may not be a realistic goal for children with intellectual disabilities. In other words, there is not always acceptance of a child’s limitations.

One participant stated that in addition to the shortage of knowledge about services, there may also be a reluctance to use services, and an acceptance of a child’s limitations because “it is the will of God.” Families may feel that it is their lot in life to care for a child with a high level of need. A parent that feels responsible for the birth of a child with a disability may also feel solely responsible for dealing with care of the child. Handing care over to others, even for limited periods of time, can lead to feelings of inadequacy, guilt, and fear of further retribution.

Contradicting this statement, a non-Tamil service provider who works with Tamil families stated that there is acceptance of services in the home, and people do want practical help. Evidence of this is seen in the fact that families are reaching out to mainstream medical and rehabilitative organizations looking for help. This could again be a sign of Tamil families who look outside the ethnic community to avoid the prejudices and assumptions of the community. Specialized “communities” that specialize in disability support and rehabilitation may be expected to provide a more welcoming atmosphere.

Another participant brought up the fact that marriage into a family who has a child with a disability is considered unwise/bad, and a child may be hidden so sons/daughters will be seen as more marriageable – there is a fear that the disability will be passed on to a family’s future generations.

Discussion moved again to supports and services in the community. It was said that while there is support from family and friends, it is a patronizing kind of support – pity. Some Tamil organizations have made progress in instituting programs to try and influence a change towards more positive attitudes.

When the group was asked to give some success stories, there was a protracted bout of cynical laughter among the group. Among the laughter, one person said that “it’s all damp.” After the laughter died down, two people did share success stories, one of whom also summarized the situation by saying that some families may hide a child with a disability, while others may go outside the Tamil community for help.

Both of these choices make it obvious that acceptance and understanding is a real problem among this community. There appear to be very strong barriers to acceptance and inclusion. While there are many Tamil-based support organizations, there seems to be little capacity within the community to provide services specific to disability, much less to initiate advocacy and idea sharing. There is also a lack of disability-specific service training among Tamil service providers. This lack of capacity adds to the need for families to go outside the community to

mainstream organizations, e.g. Ontario Works, Ontario Disability Support Program, Toronto Housing.

4. *Interview with Service Provider re: Tamil Community*

Two representatives of a service agency in Toronto were interviewed in an attempt to understand how they had been successful in initiating and maintaining relationships with members of the Tamil community.

The first reason raised was the fact that their organization performs diagnosis and assessment of disability, which is necessary for many of the government programs available to people with disabilities. They receive a large number of referrals from medical professionals for this reason – a practitioner may decide that an individual or family needs particular supports or services, and the first step to these services is assessment.

It was also mentioned that the agency has few criteria that restrict the types of disability that can be addressed/managed, while Community Living Toronto has a number of restrictions and a mandate that limits clientele.

During the time of influx of refugees to the Toronto area in the past decade, there was a substantial amount of cultural education provided to agency employees. It is unclear how this has affected the success of the organization in initiating and maintaining relationships with ethnic minority clients, however, this interview as well as that undertaken vis-à-vis the Chinese community (see below) demonstrated that employees have a wide knowledge of ethnic minority cultures in the Toronto area, a willingness to accommodate cultural differences within their rehabilitative paradigm, and support of these characteristics from upper management.

Though the agency is arguably based in a medical model of disability, it works with “the whole family,” and understands the need for respite services, adequate housing, inclusive child care, etc. The interviewees noted that the needs of the client are balanced with the needs of the family, and the connection between the agency and the client/family is seen as an important one to maintain: the intake person acts as the service broker and coordinator, providing continuity for clients. One person forms and maintains a relationship, which helps to keep the client within the organization. It was mentioned that families have many people coming in and out of their lives, and having a constant professional presence can have great meaning.

In contrast to the interview regarding the Chinese community – in which the interviewee stressed that work with Chinese families cannot be done through an interpreter, and must be done in the first language of the client – these interviewees stressed that they had several clients who were not fluent in English, but were nevertheless happy with the English-based services they received.

It was mentioned that there have been long appointments without translation, involving a lot of gestures and repeated phrases. Some people have found this difficult and discontinued service, however this has not occurred often. It was said that there is often someone in the family or in the community who can speak English and translate.

When asked about the ethnic makeup of the agency, the interviewees did not perceive the organization as significantly diverse. It was said that there are not a lot of ethnic minority recruits to draw from who have been educated in developmental services.

D. The Toronto Chinese Community

The Chinese comprise one of the largest and most distinctive communities in Toronto, and have had a presence in Canada for generations. The first recorded Chinese immigrants to Canada - seventy carpenters from Macao – arrived with British explorer John Meares on Vancouver Island in 1788. No others were recorded until 1858, when Chinese immigrants came north from the United States upon word of gold strikes in the Fraser River Valley (CBC News Online, 2004).

The age and size of this community, as well as their reputation for self-sufficiency, may lead one to expect substantial differences when compared to the Somali and Tamil communities. However, all three communities share similar problems in dealing with intellectual disability.

1. Literature Review

Statistics Canada reported the 2001 Chinese population in Toronto as 435,690 (mixed Chinese origin) and 379,555 (Chinese only origin).⁸ There are three major concentrations of ethnic Chinese in Toronto: the Trinity/Spadina municipal ward, Riverdale (fanning out from the intersection of Broadview and Gerrard) and northeast Toronto (east of Steeles & Bayview, Markham, and Richmond Hill, which is home to the majority of Toronto residents with origins in Hong Kong).

a. Engagement with Service Agencies and Organizations

Sproston et. al. (2001) have compared the Chinese community in the United Kingdom to both whites and other minority groups and found that “Chinese people in England are less likely than people from other minority ethnic groups to consult their general practitioner, even after their relative health status is taken into consideration” (189). This tendency was found especially in individuals who did not speak English. On the other hand, the presence of “self-reported long-standing illness or disability... was a significant predictor of general practitioner consultation during the previous 12 months” (193). Such individuals could nevertheless be separated into those who do and do not speak English, with those who have a long-standing illness or disability and who speak English more likely to consult with their general practitioner.

Ray-Mazumder (2001, 197) also found that “language difficulty was identified most frequently as the major barrier to accessing care among this population.” As with other studies, this one found cultural variables correlated with health service use, but also that cultural influence varied with gender and age – while young women were more likely than young men to seek care, this difference lessened with age. At a certain point, other factors became more important in health-related help-seeking behaviour (e.g. insurance status, privacy and modesty).

Wong-Hernandez & Wong (2002, 108) have attributed the underutilization of social services in Chinese-American communities (demonstrated by Leong, 1996) to “the fact that Asian Americans stress the importance of obedience and conformity to the family and the society.

⁸ Source: Statistics Canada, 2001 Canadian Census tabulations, table 97F0010XCB01001. For population clusters, see www.city.toronto.on.ca/ourcity/images/profile2_map3.gif and www.city.toronto.on.ca/ourcity/images/profile2_map5.gif.

Public admission of personal and psychological problems will bring shame to the individual and the family, and therefore is suppressed.” At the same time, Chinese (and other Asian) populations may be unclear about the role of a service provider, and “to the purpose of counselling and may expect a quick solution to their problems and direct advice as to what to do with the situation at hand” (112).

Ng (1999) has countered these assumptions by asserting that part of this underutilization may be attributed to lack of cultural awareness on the part of service providers.

b. Chinese Beliefs and Attitudinal Tendencies Towards Disability

Tse (1994) provides an anecdote of a social service agency in Hong Kong that applied to “stage an exhibition in a shopping centre.” The management of the centre would only agree to this on the condition that no persons with intellectual disabilities would be present, for fear that “shoppers would over-react.” After the organizers protested this decision, management provided a non-central exhibition space with no conditions. Tse also relates a news story that reported threats by neighbours “to burn down a hostel for adults with learning disabilities under construction or sabotage its future operation.”

As was found among the Somali community in Toronto, there appears to be a tendency within Chinese communities to confuse intellectual disability with mental health issues such as schizophrenia and bipolar depression (Tse, 1994). There is also a prevalence of ill feelings and discrimination toward people with mental health issues, which Tse attributes – whether correctly or not – to the 1982 “Un Chau Estate incident,” in which “a former psychiatric patient went berserk at a kindergarten... killing six children and wounding 40 others.” A more recent study found that, while attitudes towards mental health issues are still rather negative, they are less so towards people with intellectual disabilities (Hong Kong Health, Welfare and Food Bureau, 2002).

In literature from mainland China, there is a definite emphasis on the need for medical intervention to cure rather than to accommodate people with disabilities. Examples of this are found in a 1996 White Paper on the situation of children in China:

China has actively developed the “Three Recoveries” programme (rectifying polio sequelae, training deaf children in hearing and speech and performing cataract operations). By the end of 1995, China had rectified 360,000 children of polio sequelae (a success rate of 98%), helped more than 60,000 deaf children recover their hearing and speech abilities (10% of which had entered regular kindergartens and elementary schools to receive higher education), had provided 30,000 poor-sighted children with sight aids and helped 100,000 mentally retarded children enhance their cognitive capacity and self-sufficiency (Information Office of the State Council, 1996).

The mainstream Chinese view of disability as an individual rather than structural problem (i.e. understanding disability through a medical rather than social lens) was found by United Kingdom researcher Emma Stone: “... in China the vast majority of participants conceived disability exclusively as impairment, as the result of individual fate or bad luck, as a problem for themselves, for their families and communities” (Stone, 1997, 221). In interviews with Chinese

families, Stone found that rehabilitation and “remedial operations... were on the lists of all families interviewed as well as of several disabled adults” (Stone 1997, 222).⁹

Thompson (1997) also supports this characterization:

Chinese-American concepts of health are based on harmony with one’s natural universe while illness is evidence of being out of harmony... such cultures tend to see disability, especially psychological disability, as something shameful that has been visited upon the family by spiritual forces and, therefore, as the family’s responsibility to manage. Such beliefs often lead to a preference for and use of non-traditional medical/spiritual sources that can return the afflicted person to harmony with the group, thereby resolving the problem through in-group resources.

Perhaps since the time of Max Weber, this tendency has been attributed to Confucian ideals, which “do not... sanctify the transcendence of mundane affairs... instead they set as an ideal the harmonious adjustment of the individual to the established order of things” (Giddens, 1976, xv).

The Chinese education system is highly segregated between students with and without disabilities, with a system of special schools and special classes in regular schools. The 1996 White Paper notes that “in 1995 the national average school enrolment rate of blind, deaf and mentally retarded children reached 60%; in the economically developed areas enrolment reached 80%.”

Stone (1997) notes that “the vast majority of disabled adults in non-agricultural work are employed by social welfare factories in which half the workforce is disabled” and many of those she interviewed viewed “segregated employment better than none and, in some cases, better than non-segregated employment” (223).

In Hong Kong, Person & Yiu (1993) and Tse (1994) have written of the barriers raised against community inclusion of persons with disabilities and mental health issues because of the resistance of community members. This resistance is attributed by Tak-fai Lau & Cheung (1999) to a lack of contact between people with and without disabilities; differences in resistance was also correlated with age, level of education, and gender.

A study by the Hong Kong Health, Welfare and Food Bureau (2002) found that 66% of persons polled thought that people with intellectual disabilities should live at home with their families. At the same time, 23% of persons polled thought that people with mental health problems should “reduce their activities in public places;” eight percent thought this of people with intellectual disabilities. As well, 39% of respondents were of the opinion that service centres for people with mental health issues should not be built in their neighbourhood; eighteen percent thought this of centres for people with intellectual disabilities.

The government of Hong Kong has undertaken similar research in a variety of areas, including the school system. The Hong Kong Equal Opportunities Commission recently funded a survey of over 5000 students (University of Hong Kong, 2002), which found that while students were aware of and had positive feelings about non-discrimination, human rights and equal

⁹ This tendency is strikingly illustrated in the documentary *Wellspring* (China, 2002, 49 min; Director Sha Qing).

opportunity, these feelings did not necessarily translate to positive conceptions of disability. For example, people with mental health issues and intellectual disabilities were ranked “at the bottom” of attitude scales. It was generally thought that “people with a disability would be more comfortable and better educated in special instead of integrated schools... students were hesitant towards personal commitments and cautious about the social consequences, in particular the sense of threat and unpredictability, in relating to people with a disability.” Sixty percent of respondents had never had contact with a person with a disability. The authors of the study attributed much of this attitude to the fact that “rehabilitation and special education facilities are largely designed on segregationist assumptions. It was therefore not surprising that students thought that special settings were where people with a disability should belong.”

More positive attitudes were found among the youngest and oldest survey respondents, with middle age groups having “significantly more negative attitudes towards people with a disability.” As well, female students “were significantly more positive in their attitudes... than male students,” but no correlation to attitudes was found with education levels of parents, number of computers in the home or family composition.

Tsao (1998), in a first-person account, writes that disability is indeed “still a taboo topic within many parts of Asian cultures.” The “old school of superstitious thought teaches that disability is some sort of punishment, and promotes the idea that being different is always a horrible thing.” The author tells of being sheltered by her parents and not being allowed to attend functions if first-generation Chinese would be attending (this may imply that attitudes are changing with time). Elders were expected to look down upon a family perceived as having been punished for some past wrong. This attitude could also realistically be transformed from extrinsically- to intrinsically-experienced feelings by a person that they somehow “deserve” to have a disability. This has consequences for an individual’s feelings of self worth, and the ability to form friendships and long-term romantic and sexual relationships. In Tsao’s case, her community’s reaction to her disability led her to avoid contact, turning instead to out-group cultures where she felt more comfortable and accepted.

2. *Chinese Community Focus Group*

Compared with the focus groups held with Somali and Tamil families, the Chinese group was positive in the first part because of the number of individuals with disabilities who either were present or represented by their parents. It is not clear whether this was a factor of the organizers making calls to the right people, whether individuals and families were more likely to attend this sort of gathering, or whether the Chinese community is more acculturated to the presence of intellectual disability, its distinction from other issues, and the need to address shortcomings in the supports this population receives.

There were ten individuals or family members present at the discussion, representing a number of different types of intellectual disability. The age of individuals ranged from 13 to 40 years.

It was clear that, for recent immigrants of Chinese background, there are problems negotiating a system that is not easy to understand and navigate. For example, in terms of getting information, participants noted that they often do not know who to call to find out what supports and services

are available, and there is no way of finding out without a basic understanding of the English language (most information is in English). Participants told the group about calling a telephone number, but not being able to get information as the person answering the phone couldn't understand what they were asking for.

There is also the issue of communicating with people who neither speak the Chinese language nor have a wide understanding of Chinese culture. This was a theme that was raised regularly by a number of research participants.

Parents outlined problems finding activities for their older children to do (e.g. for adolescent or older children who are in secondary school or out of the school system). Most sit at home and watch television. Parents see that their children have potential to do something, but opportunities are more often than not closed to them, and they don't know how to move the system to help them.

Parents were also obviously not aware/not being informed of the schooling options for their school age children with disabilities. For example, the group's school-age youth were likely to be streamed into special education rather than included in regular classrooms, and most of the parents did not understand the meaning of inclusive education.

The parents in the group had obvious trouble seeing that there can be any real future for their children. It came out in the focus group that in Chinese culture there is no precedent for "dreaming" about a future for children with disabilities. One parent said that their son with a mild intellectual disability wanted to be a police officer. They just laughed and said it was unrealistic and that he could never have a job.

3. Chinese Service Provider Focus Group

In contrast with the consultations with Tamil and Somali service providers, the focus group with Chinese service providers was limited to practitioners (the majority of whom were of Chinese background themselves) who were employed by a large Toronto area children's centre. The participants represented a wide range of specialities, including social workers, family relations and resource specialists, and neurological specialists.

a. Engagement with Service Agencies and Organizations

Chinese families come into contact with the centre primarily through referrals from doctors and hospitals, and also from other families as well as school personnel. Individuals need a medical referral to be eligible to access most of the services the centre provides. Children are referred here for medical/health reasons; to take advantage of the resource-intensive setting; for specialized recreation opportunities; and to take part in research studies. All of these components make the organization a focus for a lot of traffic, and the destination for a substantial amount of funding through canvassing and corporate donations.

The organization employs a number of interpreters who speak Mandarin and/or Cantonese, and there is a high level of demand for interpretation services for Chinese clients. Though families

succeed in finding their way through referral to the centre, there is generally a need for “a lot of education,” and there is little knowledge among Chinese of services in the community (e.g. respite, recreation, home care, etc.). Language was cited as one of the most substantial barriers to knowing what services are available.

b. *Perceptions of Intellectual Disability*

When the focus group leader asked those assembled what set the Chinese community in Toronto apart from other communities with regard to issues of disability, one participant made it quite clear that it was not wise to make broad generalizations, and that there was wide variation among Chinese in beliefs, customs, acculturation, time since immigration, education level, and economic means.

It was noted, however, that the Chinese community tends to focus on specialized schools and specialized services. A definite distinction is made between children who do and do not have obvious disabilities. There is a danger that this information was skewed, given that the centre is itself a highly specialized organization that caters to children with disabilities. Families not interested in these kinds of specialized services may not be frequently encountered at the centre. On the other hand, similar tendencies have been found by other researchers (e.g. Sproston et. al., 2001; Ray-Mazumder, 2001).

Participants brought attention to the fact that Chinese families who have a member with a disability are likely to be faced with negative disability-related attitudes from members of the extended family. This poses a particular problem for families who reach out to mainstream service providers and challenge the “received wisdom” of what having a disabled family member means. This is also a problem when trying to connect Chinese individuals and families to Chinese-run support groups. These families must reconcile their own changing attitudes and beliefs with those that continue to be held by members of their extended families and communities.

An ongoing theme in the focus group was the deep feeling of responsibility many Chinese families may have concerning a child with a disability. Since it is “their child,” it is therefore “their cross to bear,” so to speak. Feelings of guilt are also an issue if a family member is in a position to be away from a disabled child. Attached to this feeling – which may lead families to reject offers of outside help, believing it is their lot in life to take care of a “problem” they are responsible for – are several other tendencies. One of these may be a problem with authority, and with taking advice from outsiders or strangers; a slightly different version of this is the feeling of “how could I leave my child with someone I don’t know?”

Another tendency mentioned by the group is a recurrent hope that a cure for disability is possible. This is particularly the case for individuals who have visible/physical disabilities. If a family accepts help, for example an assistive device such as a wheelchair, this may be an unwelcome admission that the condition is not going to change; accepting such help can signify giving up hope for a cure. There is an unexplained contradiction here – unfortunately not adequately addressed during the interviews and focus groups – between accepting “things as they are” and hoping for a cure.

The Chinese are said to valorize “minds of toughness,” meaning that emotions are not shown in public or to strangers or mere acquaintances. As well, Chinese families are less interested in finding ways of “feeling better” about having a disabled child; they are likely to be more interested in knowing what they can do to help the child or individual. Thus practical rather than coping skills may be accepted more readily by potential Chinese clients.

When asked if the group saw it as their job to educate members of the Chinese community about the conceptions of disability that guided their work, there seemed to be a consensus that this was one role that they played with clients. One participant said “we can only plant the seeds.” It was said that there was an obligation to provide knowledge and education. There was also a sense that Chinese families wanted this kind of information, and found it useful.

4. Interview with Chinese Service Provider

In a one-on-one interview with a Toronto-area service provider, two major subjects were discussed: first, the bases and consequences of Chinese attitudes and beliefs about intellectual disability; and second, why some service providers in the Toronto area have had success with this community, while others have not.

The interviewee first brought attention to the fact that many of the individuals who participated in the research had found the survey long and difficult to complete. This was particularly the case for parents, who may not have had the level of education demanded by some of the terminology. The interviewee herself had helped many parents with clarification of medical and physical terms. Some participants asked “what is the right answer?” There was a lack of understanding among some that there can be questions with no ‘right’ answers.

With reference to the first issue – attitudes and beliefs – this professional was of the opinion that disability may be seen by a Buddhist culture as a source of suffering for something a person did in a past life. Responsibility is placed directly on the shoulders of parents; this responsibility is augmented by a modern sense of genetic guilt (i.e. the belief that the child would not have a disability if one or both parents had “better genes”). To feelings of responsibility are added a strong emphasis on self-sufficiency. For example, many Chinese would not think of applying for Social Assistance or subsidized housing. This is likely to extend to other helping services such as respite and home care.

With reference to the second issue – why some service providers have been successful in reaching out to and retaining clients from the Chinese community – it was mentioned that the interviewee’s employer is a medical-rehabilitative agency, and therefore receives many referrals from doctors, hospitals, school boards and other agencies. This person was of the opinion that the agency receives a lot of calls from families because it is known that there are employees there who speak Chinese. They also stated that their employer has a good multicultural contingent of staff.

The interviewee noted that while the organization does not necessarily receive funding to address the needs of minority ethnic groups specifically, supervisors actively encourage employees to

initiate and maintain relationships with members of, in this case, the Chinese community. This support allowed the interviewee to spend the time necessary managing these relationships.

Some of the organization's programs include management of a support group for Chinese parents who have a child with a disability, and coverage of the costs of the group's mailing list. The centre also provides programming in Cantonese for teens with developmental disabilities.

While it was stressed that there is a definite need for the expansion of agencies like Community Living Toronto into ethnic Chinese communities, it was also stressed that this kind of work cannot be done properly through translation. It was suggested that, for an agency to properly reach out to ethnic minority communities who may not share a similar philosophy about intellectual disability, it must train and employ people from similar cultural backgrounds.

VI. Summary of Findings

A. General Observations

- Chinese, Tamil and Somali communities are more likely, on the whole, to access medical and rehabilitative services than to access support services such as respite, home care, and supported recreation.
- The likelihood of individuals from these communities accessing medical, rehabilitative and support services is affected by a variety of factors, including proficiency in the English language (more proficient, more likely), gender (women more likely than men), age (young and old more likely than middle age), education level (more education, more likely), acculturation to the wider community, and time since immigration to Canada (more recent, less likely).
- Individuals and families need help and education on how to access the bureaucracy of the support services infrastructure. Many do not understand how the system works, and thus do not access supports and services that are available (e.g. Ontario Disability Support Program, Community Care Access Centres, inclusive child care).
- While each group examined in the current research has a well-developed support infrastructure, this infrastructure does not adequately serve the needs of group members with disabilities and their families.
- Each group examined in the current research has recently taken action to organize in the service of persons experiencing mental health problems. Education and organization in the service of persons with intellectual and other disabilities is a logical extension of this action.
- In each group examined, we have learned of a tendency for some group members to look outside the group for help and support with regard to intellectual disability. Such individuals can be assumed to be attempting to escape negative attitudes associated with the group. These individuals could serve as important agents of attitude change within ethnic minority communities.
- All three groups examined have experienced some form of racism and/or discrimination, and are the subject of various misconceptions (e.g. that Tamil organizations and charities support Sri Lankan Tamil terrorists; that Somalis are likely to commit welfare fraud and are a drain on the social support system; that the Chinese were responsible for the spread of SARS in Toronto). It is thus likely that some group members may be cautious about interactions with and providing information to white service providers who do not speak the client's first language.
- Group members may be reticent about uncovering the presence of disability within families for fear of jeopardizing citizenship status or marriage opportunities for other family members.

- Though this factor is influenced by level of education, each group has a tendency towards a belief in fatalism, for example that the presence of intellectual disability is “God’s will,” a test of personal strength and belief, “meant to be,” etc. Any efforts to change a family or individual situation may be viewed as a dangerous affront to the status quo.
- More recent immigrants from each of the groups are likely to need support and information about schooling options for children with disabilities not fluent in the English language.
- None of the groups studied appear to be characterized by high levels of informal support for persons with a disability. Caregiving was reportedly confined for the most part to parents, grandparents and siblings.
- Several individuals participating in the research had connected with other agencies (e.g. Bloorview MacMillan Children’s Centre, Surrey Place Centre, Adventure Place), but claimed to have never heard of, or been referred to, Community Living Toronto.
- Individuals and families may remain hopeful that a person with a disability can eventually be cured. Acceptance of help – particularly help that is obviously long-term (e.g. assistance for purchase of a wheelchair) – may be seen as acceptance that a person will never be cured. The transition from hope to acceptance may have serious effects upon family functioning.
- There is great stigma attached both to individuals with disabilities and their families. Traditional stigma may combine with genetic guilt, as well as beliefs about heredity, to increase the likelihood that a family member with a disability will be hidden from the community.

B. The Somali Community

- Somalis suffer from multiple forms of exclusion (e.g. employment, housing, administration problems related to a lack of official citizenship documentation), therefore the problems associated with intellectual disability may not be seen as a primary service need.
- It was by far the most difficult to contact members of the Somali community, and to enjoin them to attend interviews and focus groups. This group will almost certainly require significant outreach and education about the need for and value of support services.
- Somalis may be unaccustomed to the “culture of paper” that characterizes Canadian administrative practice. This may combine with a need for higher-than-average levels of privacy to pose significant barriers to outreach, education, and service engagement.
- Somalis may also be unaccustomed to the “culture of punctuality” that characterizes Western society in general. Different conceptions of time, as well as a lack of previous experience accessing professional services, may result in differences in expectations between clients and service providers.

- There is confusion in the Somali community between intellectual disability and mental health. Further, popular conceptions of illness are very different from the medical rationalism of Europe and North America. A person's health may be seen in stark either/or terms of healthy/sick. Understandings of causation of illness may not be confined to physical and/mental bases.

C. The Tamil Community

- Two major barriers to Tamil community use of health and other support services are (1) lack of knowledge about what services are available, and (2) lack of English language skills/shortage of information in the Tamil language.
- In addition to access barriers such as lack of knowledge about services and shortage of services in the Tamil language, psychological barriers (e.g. shame, embarrassment, fear that time will be wasted filling out forms and dealing with service providers) may play a role in low service use in the community.
- There seemed to be a lack of emphasis on independent living for persons with disabilities in the Tamil focus groups. It appears that people with disabilities are viewed with pity, and as being incapable of thriving to the same extent as people who do not have disabilities.
- There is a lack of emphasis on "caring for the caregiver" in the Tamil community.
- Tamil individuals and families may be more comfortable looking outside their ethnic community for help and support. In other words, some Tamils may identify more as disabled individuals, or as families with a member who has a disability, than as belonging to the Tamil community.
- The Organization of Canadian Tamils with a Disability will be a valuable connection to the community. The group has begun a database of individuals with disabilities, and has organized a conference on disability in Toronto in the recent past.
- Tamils are said to value education, and place high expectations on children to become doctors, lawyers, and other kinds of professionals. Acceptance of a child's limitations can therefore be a difficult process.

D. The Chinese Community

- Chinese Canadians may be the least likely of the groups studied to contact outside help for health and other problems. This is especially the case for those not proficient in the English language.
- Obedience, conformity, and maintaining the status quo are prevalent values within Chinese communities. There is great value in "keeping face," (i.e. maintaining strength of character

and the position of one's family) and great possible loss in "losing face" (i.e. seeming weak or bringing shame to one's family).

- Perhaps more than the other groups studied, it is important for service providers working within the community to demonstrate an understanding of Chinese culture (e.g. particular customs, language, region of familial origin, etc.).
- Chinese may be more likely than other groups to look for practical rather than emotional help, and services that emphasize the well-being of the person with a disability rather than the family.
- Chinese individuals and families may be biased toward looking for cures and solutions rather than ongoing supports.
- Chinese parents are likely to see a child with a disability as their own responsibility, stemming from a strong belief in self-sufficiency. Asking for help may be seen as a failure to fulfill their parental duty.

VII. Discussion

For the groups studied in the current research, and perhaps for many groups distinguished by non-Western ethnicity, the relevant issues which most lead to (1) a negative valuation of persons with disabilities, and (2) low likelihood of positive engagement with service and support agencies, can be subsumed under a four word heading: language – understanding – shame – fear.

First of all, *language* was often identified during the research as the primary barrier to engaging both with North American philosophies about intellectual disability and with disability-focused service providers. A lack of available information in languages other than English, and a lack of fluency in the Somali, Tamil, and Chinese languages among information and service providers, present major access barriers to both long-resident as well as recent first generation immigrants.

This appears to be particularly the case for the Chinese community, where a lack of facility in the Chinese language may be interpreted as a sign of ignorance of Chinese culture. There is evidence that one does not have to be ethnic Chinese to be considered “Chinese” (see, for example, Gillette, 2002). However, service providers unable to demonstrate a knowledge of Chinese culture may be unlikely to have great success among families who, unlike those who may take the initiative to go outside the community, are strongly tied by ethnicity to their community.

Second, there is a lack of *understanding* of the causes of intellectual disability, as well as of the lives of persons with intellectual disabilities. This lack of understanding combines with beliefs about intellectual disability that serve to separate stigmatized persons from the group. Such beliefs range from the idea that disability is a punishment for deeds performed in a past life, to the idea that a disability is “God’s will” (a belief also characteristic of Christian ideology), to the idea that a parent is solely responsible for their offspring.

While not limited to non-Western ethnic communities, these types of beliefs can lead to a range of problems: guilt and an emphasis on self-sufficiency can lead to concealment, which can lead to increased stress, family breakdown, abuse, and a general low quality of life for individuals with disabilities.

Lack of understanding is a gateway to the third word in the heading: *shame*. Individuals as much as their family members may be ashamed of their condition, and may be removed or remove themselves from the life of the community. Needed supports and services may be foregone because of the shame connected with receiving help outside the family, or because a need for help signals to the community (or to a family in denial) that there is a problem.

Stigma was identified as a major problem in all three of the groups studied. Highly visible disabilities are more stigmatized, and people with these kinds of conditions are more likely to be hidden and excluded from the community. This stigma is increased by the belief in and hope for a cure, and the denial that disabilities are lifelong conditions rather than diseases or illnesses.

The fourth issue – *fear* – stems from both belief and experience. Erroneous beliefs about the causes and consequences of disability may lead to fear of being discovered as a parent of a child with a disability, or as an individual with a disability; fear also leads non-disabled individuals to

avoid those who have been stigmatized. With discovery comes the risk of bringing shame to oneself and one's family; the risk of ruining a sibling's chances for marriage; and the risk of being perceived differently from other individuals and families.

Fear can also stem from the experience of exclusion. There is evidence that individuals with disabilities are regularly excluded from social gatherings. Parents reportedly often deal with the ignorance and shame of members of their extended families. An individual or family that has been regularly excluded from social gatherings, or that has had a negative experience with a member of the community, a service provider or a health professional, may be discouraged from looking for help and support. A child who is treated as a burden, a punishment, or as a person (or half-person) with a long-term sickness may experience persistent feelings of worthlessness and learned helplessness.

These issues are unlikely to be affected or resolved within a closed system. Based on the research, service agencies must, if they wish to reach into the communities studied, address a number of their own access barriers that stem from too strong a focus on the needs of mainstream Canadian individuals and families. A number of recommendations towards accomplishing this type of organizational change were raised during research consultations.

VIII. Recommendations

Research participants suggested a number of ways that mainstream Canadian service agencies could make inroads into their communities. These suggestions deal mainly with information provision, education, and trust, and include the following:

1. Produce a series of brief information flyers (in Mandarin and/or Cantonese, Tamil, and Somali languages) describing the organization, and the services it provides. These flyers should optimally be composed in consultation with ethno-cultural organizations, and initial versions should be field-tested in limited sections of particular communities.
2. Produce of series of brief information flyers on intellectual disability, catering to specific groups, which address the specific issues identified in this report. For example, flyers in Somali would focus on distinguishing between mental health and intellectual disability, and would briefly quote a medical professional on the biological causes of disability. Flyers could also address the myths of causation (e.g. punishment by God, inhabitation by spirits, seeing a disabled person while pregnant, etc.). The Canadian Mental Health Association has produced a series of materials that could serve as examples to build on.¹⁰
3. Establish ongoing relationships with ethno-cultural organizations and settlement workers willing to dedicate resources to learning about intellectual disability, networking with individuals and families, accepting and photocopying flyers, etc.
4. As much as possible, offer service coordination in the first language of the client, either through interpretation or employment of staff fluent in languages other than English.
5. Strengthen relationships with medical and rehabilitative organizations such as the Bloorview MacMillan Children's Centre, Surrey Place Centre, and the Hospital for Sick Children. Though Community Living Toronto is known to these organizations, there is evidence that this knowledge is not being passed on to clients. It is possible that CLT waiting lists and/or lack of diversity may be hindering referral.
6. Strengthen relationships with Toronto area schools. Community Living Toronto currently receives a substantial number of referrals from the school system; however, the organization's problems serving ethnic minority families suggests that these relationships could be renewed with an emphasis on CLT willingness to focus partially on the needs of immigrant children and youth with intellectual disabilities.
7. There is a dual information challenge in ethnic minority communities: (1) the challenge of reaching individuals and families connected to ethno-cultural settlement, recreation, and culture-based organizations; and (2) the challenge of reaching individuals with disabilities and family members who avoid these organizations because of cultural-specific stigma. Therefore both a targeted (1) and diffuse (2) information dissemination strategy is needed to reach the widest audience possible.

¹⁰ See http://www.toronto.cmha.ca/c_what_we_do/wwd_publications.asp.

8. Many organizational representatives who were interviewed, and who participated in focus groups, offered help and space for CLT to run educational and informational talks and workshops. For the Somali Community, Dixon Community Services is located near a high density Somali population. A group of “community elders” meets every Friday at Dejinta Beesha, where one short but successful information session was already held. The Organization of Canadian Tamils with a Disability is an obvious choice for the Tamil community. CLT has already established connections with Chinese professionals who could provide access to these kinds of opportunities.
9. Interest was also expressed in having a video of actual Somalis, Tamils and Chinese individuals telling their stories. Given that many access barriers exist within the ethno-cultural communities themselves, the opportunity for community members to see other members facing these issues may help to overcome belief and attitudinal barriers.
10. All three communities have a rich network of newspaper, online, and radio audiences. Somalis especially stressed the utility of providing information through the weekly radio show hosted by CHIN (AM 1540) on Sunday nights, which is reportedly listened to by a very large proportion of the community. CHIN also offers programming in Cantonese during the week from 1:00 to 6:00 pm. Tamil programming is available through the use of a special radio that can be purchased from some Tamil-owned stores in the Toronto area. These avenues would be particularly helpful in reaching those persons afraid of asking for help from ethno-specific organizations.
11. Work with ethno-cultural organizations to establish support groups for individuals with disabilities and their families. This would allow those touched by disability to “come out of hiding” and connect with others facing similar situations in a safe environment.
12. Establish a database of ethno-specific organizations willing and able to consider taking referrals from Community Living Toronto.
13. Ensure that Community Living Toronto is a learning organization. Require employees to maintain up-to-date knowledge of emerging research in human services; provide employees with opportunities to maintain and update knowledge stores; support employees to move and grow within the organization; provide employees with real opportunities to provide their knowledge and experience to management.

IX. Conclusion

This report, and the research out of which it has grown, has focused on the experience and understanding of intellectual disability in the Chinese, Somali and Tamil communities in Toronto. It found that, regardless of ethnicity, individuals with disabilities and their families are likely to share the experience of exclusion.

Culture-specific attitudes that are unwelcoming and unsupportive of people with disabilities and their families are the result of generations of influence from religion, philosophy, government, folklore and experience. This is no less true of mainstream “white” culture in Canada than for ethno-cultural minority communities.

The research points to the need for these communities – which have enormous strengths and capacity for inclusion and mutual support – to develop more supportive approaches to people with intellectual disabilities and their families. In some areas, specifically around mental health issues, progress is already being achieved. However, these communities stand to learn much from the decades of learning that organizations like Community Living Toronto have been able to acquire.

For mainstream service agencies to connect with and meet the needs of ethnic minority communities, the organizations will themselves need to commit to openness and constant learning. They will have to find ways of appreciating and accommodating the cultural needs that are specific to ethno-cultural minority communities, without which such community members are unlikely to feel welcomed into the community living vision. Mainstream agencies will also need to adopt non-dogmatic approaches to culture-specific understandings and attitudes towards disability, recognizing that there is much room for improvement in all communities regardless of whether they comprise minority or dominant groups.

This will not be an easy or short-term undertaking. It will require new forms of dialogue and partnership, the building of mutual trust, and interactive learning of how best to explore, frame and communicate the place and value of people with intellectual disabilities and their families. It is The Roeher Institute’s hope that the present research has provided a good starting point for fostering that dialogue, partnership and learning.

X. References

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Appendix – Survey of Families of Children with Disabilities

Overview

This survey asks questions about the needs and experience of families of persons with disabilities from Tamil, Somali and Chinese communities in Toronto.

The survey explores many issues that may be important to families of persons with disabilities, and how living in a specific ethnic community may affect their experience of disability. The survey asks questions about:

- Who the person is and who is in their life, including family members, friends, support workers, and others
- What the person may need personally or because of their family member's disability (either because of physical or mental difficulty or because of barriers outside the person that wouldn't be an issue if the person didn't have a disability)
- Experiences at home, school, work or in the community related to families' needs, hopes and dreams
- The ability of your community to meet your needs and the needs of its members with disabilities

At the end of the survey there is space to provide whatever other comments you would like to make. Feel free to add additional pages for comments if you think this would be useful to the research.

Personal Information

The information requested below will tell us about your age, sex, personal experience with immigration and disability etc.

Information will be held in strictest confidence: **What you say will not be shared with anyone beyond The Roeher Institute for any reason.** In any research reports based on information you give, none of the information will be attributed or traceable to you, personally, or to the organization with which you are affiliated. **We will use your words, but it will be impossible to know who said them.**

Please complete the following information. It is important for the analysis of survey responses.

Please place all your answers in the right-hand column. For questions where a number of options are provided, choose the number that matches the option that most applies to you. Answers to open-ended questions should also be written in the right-hand column. Please provide us with detailed information; the space will expand to accommodate what you write.

Here is an example of how your answers might look:

EXAMPLE

Write your answer HERE
white spaces only!
↓

10.	Languages spoken and understood:	English French Tamil Chinese Somali Other	1. 5. 6.
a.	Other languages (specify)		Swahili
104.	What are the biggest barriers that keep you from fulfilling participating in life in the community?		The accessible transportation service is not dependable. Sometimes in comes an hour late to take us where we need to go and then it picks us up an hour early. If it's only a three-hour event, we end up missing most of it.

After completing the survey, **please save your file** so that your answers are not lost.

Okay, now let's get to the real survey!

Survey on Needs and Experiences of Families with Members with Disabilities

Write your answer
HERE
white spaces only!
↓

Personal Information		
1.	First name	
2.	Last name	
3.	Preferred mailing address:	
a.	Street	
b.	City / town	
c.	Province	
d.	Postal code	
e.	Home telephone	
f.	Work telephone	
g.	TDD/TTY (if applicable)	
h.	e-mail	
4.	Do you provide informal support to one or more:	
a.	Family members with disabilities	1. Yes 2. No
b.	Friends / neighbours with disabilities	1. Yes 2. No
Demographics		
5.	Year of birth	
6.	Sex	1. Male 2. Female
7.	Does one of your family members have a disability?	1. Yes 2. No
8.	What is his/her relationship with you?	
9.	Your Marital Status:	1. Single 2. Married 3. Divorced 4. Separated 5. Widowed
10.	Languages spoken and understood:	1. English 2. French 3. Tamil 4. Chinese 5. Somali 6. Other
a.	Other languages (specify)	
11.	Schooling completed	1. Less than Grade 8 2. Elementary School 3. Some High School 4. High School Diploma 5. College Diploma 6. Bachelor Degree 7. Masters Degree 8. PhD
12.	Present status:	
a.	Are you currently in school?	1. Yes 2. No
b.	Are you currently working?	1. Yes 2. No

Write your answer
HERE
white spaces only!



13.	If you are in school, what level of school are you in	1. Elementary 2. Secondary 3. Post-Secondary	
14.	If you are in school, what kind of school are you in?	1. Regular Class in Community School 2. Special Class in Community School 3. Special School	
15.	If you are in school, is your school:	1. Full-time 2. Part-time	
16.	Present employment	1. Are you currently working for pay? 2. Are you currently working as a volunteer or unpaid family worker? 3. Are you both working for pay and volunteering?	
17.	What kind of work do you do?		
18.	Is your work?	1. Full-time 2. Part-time 3. Contract	
19.	Were you born in Canada?	1. Yes 2. No	
20.	What year did you come to Canada?		
21.	What is your country of birth?		
22.	Why did you leave to come to Canada?	1. War 2. Economic Trouble 3. Family Reunification 4. Wanted better life 5. Other	
a.	Please specify other		
23.	What type of housing are you in?	1. Single detached home 2. Double, duplex or town home 3. Apartment 4. Shelter or temporary housing	
24.	Do you own or rent your housing?	1. Own 2. Rent	

25.	How many people live with you in your home?	<ol style="list-style-type: none"> 1. 1 2. 2-3 3. 4-5 4. 6-8 5. More than 8 	
26.	How many bedrooms do you have?	<ol style="list-style-type: none"> 1. One 2. Two 3. Three 4. Four 5. Five 6. Six 7. More than 6 	
27.	Please indicate whether you have been told that your family member has a long-term health condition or disability that is expected to last six months or longer that affects his/her:	<ol style="list-style-type: none"> 1. Hearing 2. Seeing 3. Speaking 4. Mobility 5. Agility/Flexibility 6. Learning 7. Thinking/Memory 8. Mental Health 9. Other 	
a.	Please specify other		
28.	Have you ever been told that your family member has an intellectual or developmental disability?	1. Yes 2. No	
Thinking about your family member with a disability, please provide us with information about her/his needs and circumstances:			
29.	In what type of residence does your family member with a disability live now?	<ol style="list-style-type: none"> 1. With you 2. Independently on own or with others with support 3. Community residence (e.g. group home, supported living for a group) 4. Foster/alternative family (for children/ youth or adults) 5. Temporary, transitional, or emergency housing 6. Nursing home, extended care 7. Institutional facility 8. Not applicable 	

30.	Which one of the following best describes the CAUSE of your family member with a disability's condition? (One answer only)	<ol style="list-style-type: none"> 1. Present at birth 2. Disease/Illness 3. Natural ageing process 4. Work conditions 5. Stress 6. Accident – home 7. Accident – motor vehicle 8. Accident – work 9. Psychological or physical abuse 10. Other: 	
a.	Please specify other		
31.	What kinds of supports does your family member with a disability need:		
a.	General activities of daily living including attendant service, home care and homemaking assistance	1. Yes 2. No	
b.	Accessing and participating in Early child development (including child care, pre-school programs)	1. Yes 2. No	
c.	Accessing and participating in Primary and Secondary School	1. Yes 2. No	
d.	Accessing and participating in Post-Secondary Education	1. Yes 2. No	
e.	Accessing and participating in Adult Education and Vocational Training	1. Yes 2. No	
f.	Individual planning and / or service coordination (case management, service brokerage, etc.)	1. Yes 2. No	
g.	Information and referral to needed supports and services	1. Yes 2. No	
h.	Life/Social Skills Development	1. Yes 2. No	
i.	Medical care and rehabilitation (therapies, prosthetics, medical treatment, medication)	1. Yes 2. No	
j.	Accessing and supporting involvement in Community/Recreation activities	1. Yes 2. No	
k.	Accessing or using Public Transportation	1. Yes 2. No	
l.	Other	1. Yes 2. No	
m.	Please specify, other:		
32.	How is the need for support for your family member with a disability determined?	<ol style="list-style-type: none"> 1. Self-determined 2. Determined/identified by family member 3. Physician or other mandated health professional 4. Mandated social worker or other social services professional 5. Other 	
a.	Please specify, other:		

Please indicate the supports and services to which your child has access:		
33.	Hearing difficulties	
b.	A computer to communicate	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
c.	A volume control telephone	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
d.	A TTY or a TTD	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
e.	A message relay service	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
f.	A closer caption TV or decoder	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
g.	Amplifiers, acoustics, infrared	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
h.	Visual or vibrating alarms	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
i.	Sign language interpreter	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
j.	Hearing ear dog	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
k.	Other	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
l.	Please specify other	

34.	Seeing difficulties	
a.	Magnifiers	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
b.	Braille reading materials	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
c.	Large print reading materials	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
d.	Talking books	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
e.	Recording equipment or portable note-takers	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
f.	Computer with Braille, large print or speech access	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
g.	A white cane	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
h.	A guide dog	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
i.	Other	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
j.	Please specify other	
35.	Mobility difficulties	
a.	Orthopedic footwear	<ol style="list-style-type: none"> 5. Yes, full access 6. Yes, partial access 7. They need but do not have 8. They do not need
b.	A cane or walking stick	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need

c.	Crutches	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
d.	A manual wheelchair	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
e.	A walker	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
f.	A scooter	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
g.	Braces or supportive devices	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
h.	Lifts or lift type devices	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
i.	Grab bars or bathroom aids	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
j.	Other	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
k.	Please specify other		
36.	Agility difficulties		
a.	Portable spell checkers	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	

b.	Recording equipment	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
c.	Talking books	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
d.	Pocket organizer	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
e.	A home computer	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
f.	Scanner or printer	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
g.	Spell/grammar checking software	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
h.	Voice recognition software	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
i.	Software organizational tools	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
j.	Other	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need 	
k.	Please specify other		

37. Communication difficulties		
a.	Portable spell checkers	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
b.	Recording equipment	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
c.	Plain Language books	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
d.	Pocket organizer	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
e.	A home computer	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
f.	Scanner or printer	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
g.	Spell/grammar checking software	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
h.	Voice recognition software	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need
i.	Software organizational tools	<ol style="list-style-type: none"> 1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need

j.	Magnifying Software	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	
k.	Blissboard	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	
l.	Note takers, scribes or readers	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	
m.	Interpreter – Personal Assistant	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	
n.	Text Chat e.g. Access to electronic chat rooms	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	
o.	Electronic Whiteboards	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	
p.	Other		
38.	Health difficulties		
a.	Medication and Drugs	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	
b.	Respiratory Aids e.g. inhalers, puffers, oxygen	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	
c.	Pain Management Aids e.g. a TENS machine	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	

d.	Regular medical treatments e.g. Dialysis	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	
e.	Personal Health Care and Incontinence Supplies e.g. Insulin equipment, monitors, syringes, catheter tubing, portable emergency call system, colostomy supplies, feeding equipment and supplies, diapers, etc.	1. Yes, full access 2. Yes, partial access 3. They need but do not have 4. They do not need	
f.	Other		
g.	Please specify other		
39.	Other difficulties		
a.	Other		
b.	Please specify other		
40.	If your family member with a disability needs one of the previous aids but he/she does not have, why does he/she not have it?	1. It is not covered by insurance 2. It is too expensive 3. His/her condition is not serious enough 4. You do not know where to go to obtain it 5. It is not available 6. Another reason	
a.	Please specify another reason		
41.	Does your family member with a disability usually receive help with:		
a.	Preparing meals	1. Yes 2. No	
b.	Getting to appointments and running errands (such as shopping from groceries)	1. Yes 2. No	
c.	Looking after his/her personal finances (such as paying bills)	1. Yes 2. No	
d.	Child care	1. Yes 2. No	
e.	Personal care	1. Yes 2. No	
f.	Nursing care or medical treatment at home (such as injections, therapy, blood, etc.)	1. Yes 2. No	
g.	Moving about inside your residence	1. Yes 2. No	
h.	Carrying out tasks at school	1. Yes 2. No	
i.	Carrying out tasks at work	1. Yes 2. No	
j.	Carrying out tasks at recreational and/or other community activities	1. Yes 2. No	
42.	Who usually provides your family member with a disability the help that he/she needs:		
a.	You and family living with him/her	1. Yes 2. No	
b.	Family not living with him/her	1. Yes 2. No	
c.	Friends and neighbors	1. Yes 2. No	
d.	Tutor/teacher's aid/teacher/personal assistant	1. Yes 2. No	
e.	Organization or agency (include voluntary, private and government agencies)	1. Yes 2. No	

f.	Other	1. Yes 2. No	
g.	Please specify, other		
43.	Who pays for the help that your family member with a disability receives?	1. No one, it is free 2. Himself/herself 3. Family living with him/her 4. Family not living with him/her 5. Private health insurance 6. Home care program 7. Voluntary organization 8. Other private source 9. Other public source, e.g. government health insurance plan 10. Other	
a.	Please specify, other:		
	Please write a number on a scale from 1 to 4 that best describe your agreement with the statement being made where: 1. Never 2. Less than once a month 3. At least once a month 4. At least once a week		
44.	In the past 12 months, how often has your family member with a disability seen or talked about his/her physical, emotional or mental condition with:		
a.	A physician (including general practitioners and specialists)	1. Never 2. Less than once a month 3. Once a month 4. Once a week	
b.	A Physiotherapist or occupational therapist	1. Never 2. Less than once a month 3. Once a month 4. Once a week	
c.	An audiologist or speech therapist	1. Never 2. Less than once a month 3. Once a month 4. Once a week	
d.	A chiropractor	1. Never 2. Less than once a month 3. Once a month 4. Once a week	
e.	A massage therapist	1. Never 2. Less than once a month 3. Once a month 4. Once a week	

f.	A psychologist, social worker or counselor	1. Never 2. Less than once a month 3. Once a month 4. Once a week	
g.	Another health care or social service provider	1. Never 2. Less than once a month 3. Once a month 4. Once a week	
h.	Please specify another care or social service provider		
		Please write a number on a scale from 1 to 5 that best describe your agreement with the statement being made where: 1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
45.	Are you able to receive all the medical assistance that your family member with a disability needs to have a good quality of life?		
a.	All the medications he/she needs?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	All the specialized medical equipment he/she needs?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
46.	Do you ever have to wait a long time to get an appointment for your family member with a disability to see a doctor or other therapist?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
47.	Has your family member with a disability ever felt sick or had trouble breathing because of the quality of the air?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
48.	Do you ever worry about how safe the air is that you and your family members breathe?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
49.	Do you and your family members get enough healthy food to eat?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
50.	Do you or your family members ever go to bed feeling hungry?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time	

		5. Regularly	
51.	Do you or your family members ever go to school or work feeling hungry?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
52.	Do you or your family members ever use a food bank or beg for food or money?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
Your personal attitudes and traits:			
	Read each item and decide whether the statement is true or false as it pertains to you personally.		
53.	I never hesitate to go out of my way to help someone in trouble.	1. True 2. False	
54.	I have never intensely dislike anyone.	1. True 2. False	
55.	There have been times when I was quite jealous of the good fortune of others.	1. True 2. False	
56.	I would never think of letting someone else be punished for my wrong doings.	1. True 2. False	
57.	I sometimes feel resentful when I don't get my way.	1. True 2. False	
58.	There have been times when I felt like rebelling against people in authority even though I knew they were right.	1. True 2. False	
59.	I am always courteous, even to people who are disagreeable.	1. True 2. False	
60.	When I don't know something I don't at all mind admitting it.	1. True 2. False	
61.	I can remember "playing sick" to get out of something.	1. True 2. False	
62.	I am sometimes irritated by people who ask favours of me.	1. True 2. False	
Thinking now about your own needs and circumstances as a person providing care to a family member with a disability, please answer the following questions:			
63.	What kind of support do you need because you have a family member with a disability:		
a.	Modified/flexible work schedule so that you can provide the needed supports to your family member with a disability	1. Yes 2. No	
b.	Respite care	1. Yes 2. No	
c.	Child care or care for an older family member with a disability so that you can participate in community activities, attend school, work, etc.	1. Yes 2. No	
d.	Other:	1. Yes 2. No	
e.	Please specify, other:		

Please write a number on a scale from 1 to 5 that best describe your agreement with the statement being made where: 1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly		
Your feelings		
64.	Do you feel that your family is accepted by:	
a.	Your parents?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly
b.	Your brothers and/or sisters?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly
c.	Your children?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly
d.	Other relatives?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly
e.	Your friends?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly
f.	Your neighbours?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly
g.	Members of your community?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly
h.	Your doctor or other support workers?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly

i.	Your coworkers?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
j.	Other adults?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
65.	Do you feel valued by:		
a.	Your parents?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	Your brothers and/or sisters?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
c.	Your children?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
d.	Other relatives?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
e.	Your friends?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
f.	Your neighbours?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
g.	Members of your community?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	

h.	Your doctor or other support workers?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
i.	Your coworkers?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
j.	Other adults?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
66.	Do you feel that because your family member has a disability that you are treated differently than other families by:		
a.	Your parents?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	Your brothers and/or sisters?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
c.	Your children?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
d.	Other relatives?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
e.	Your friends?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
f.	Your neighbours?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	

g.	Members of your community?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
h.	Your doctor or other support workers?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
i.	Your coworkers?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
j.	Other adults?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
67.	Do you ever hear people calling you names because you have a family member with a disability?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
68.	Do you ever feel that people treat you in a disrespectful way because you have a family member with a disability?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
69.	Do you ever feel that people are always trying to tell you how to fix your family member with a disability?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
70.	Do you ever wish that people would just accept your family member with a disability as he/she is?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
71.	Do you ever feel frustrated because people don't understand what you are trying to tell them?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
72.	Do you ever feel frustrated because people don't listen to what you want?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	

73.	Do you ever feel that people from your community		
a.	Expect that you hide your family member with a disability at home so no one can see him/her?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	Expect that you are able to help your family member with a disability with whatever was needed without asking for help from others?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
c.	Expect that you do not want a stranger from another culture coming into your home to help your family member with a disability?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
d.	Accept you and your family member with a disability and offer their help with whatever is needed?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
e.	Are you given opportunities to make your hopes and dreams come true?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
74.	Do your hopes and dreams ever come true?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
75.	Are you happy with yourself as a person?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
76.	Are you happy about your life in your family?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	

77.	Are you happy with your friendships?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
78.	Are you happy with your relationship with your coworkers?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
79.	Are you happy with your relationship with your family member with a disability doctors or other support workers?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
80.	Are you treated fairly compared to other families with a family member with disability?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
81.	Are you treated fairly compared to other families without a family member with disability?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
Activities, supports and services			
82.	Do you play games, go to social events or go on outings with your family?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
83.	Do you have a chance to meet and become friends with other adults who have a similar family situation to yours?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
84.	Do you have a chance to meet and become friends with other adults who don't have a similar family situation to yours?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
85.	Do you ever think that you and your friends would do different activities if you did not have a family member with a disability?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	

86.	Do you ever have difficulty doing things with other families because:		
a.	You don't have special supports or equipment needed for your family member disability?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	You don't have accessible transportation when you need it?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
c.	Of communication difficulties?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
d.	You were not wanted?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
87.	Do you have the necessary supports to assist your family member with a disability with:		
a.	Hearing or speaking (e.g., interpreters)	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	Seeing (e.g., interveners)	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
c.	Mobility / agility (e.g., attendants)	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
d.	Intellectual issues (e.g., advisor; personal guide; mentor; tutor)	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
e.	Emotional well-being (e.g., emotional counseling)	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	

f.	Communication (e.g., note takers, scribes, readers, interpreters, peer support)	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
g.	Other	6. Never 7. Hardly ever 8. Some of the time 9. Most of the time 10. Regularly	
h.	Please specify, Other:		
88.	Do you have the equipment, supports and services you need to be fully included at work:		
a.	To participate in work activities?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	To do your work as well as you would like?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
c.	To pursue the career of your choice?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
89.	Do you have the supports and services you need to be fully included in recreational, cultural and social activities in the community:		
a.	To participate in the same activities as other people your age?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	To take the kinds of classes/courses or play the sports you would like?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
c.	To pursue your dreams?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
90.	Do you have the:		

a.	Skills and training to fully support your family member with a disability?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	Supports and services to fully participate and be included in the job of your choice?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
Your Health			
91.	Do you feel that your health is negatively affected because of:		
a.	The care you have to provide for your family member	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	The lack of supports available for you to provide care	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
Your Involvement			
92.	Do you ever feel that you do not have enough information about your family member disability or health condition?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
93.	Are you ever invited to participate in the planning of activities, games or outings:		
a.	At home?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	At school or work?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
c.	In the community?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	

94.	Are you ever invited to participate in planning the kinds and level of supports and services your family member with a disability requires to be fully included:		
a.	At home?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	At school or work?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
c.	In the community?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
95.	Are you ever invited to participate in assessing/ evaluating the kinds and level of supports and services that your family member with a disability requires to be fully included:		
a.	At home?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	At school or work?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
c.	In the community?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
96.	Are you ever invited to participate in making decisions about your family member with a disability life:		
a.	At home?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
b.	At school or work?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	

c.	In the community?	1. Never 2. Hardly ever 3. Some of the time 4. Most of the time 5. Regularly	
97.	Please tell us what you feel would make your life better at home:		
98.	Please tell us what you feel would make your life better at school or work:		
99.	Please tell us what you feel would make your life better in the community:		
100.	Please tell us what you feel would make your life better with your friends:		
101.	What are the biggest barriers that keep you from fulfilling participating in life at home?		
102.	What are the biggest barriers that keep you from fulfilling participating in life at school or work?		
103.	What are the biggest barriers that keep you from fulfilling participating in life in the community?		
104.	If you feel that people laugh at you or treat you in a disrespectful way, can you tell us why you think that they do that?		
105.	What would you like to do more than anything else in the world?		
Future Directions			
106.	Looking towards increasing the inclusion of persons with disabilities and their families in the future, what are the one or two most important things...		
a.	<i>...that governments and government programs and services could or should be doing that they're not already doing?</i>		
b.	<i>...that community-based service organizations (e.g. recreation and arts programs, youth groups, etc.) could or should be doing that they're not already doing?</i>		
c.	<i>...that disability-specific agencies could or should be doing that they're not already doing?</i>		
d.	<i>...that teachers could or should be doing that they're not already doing?</i>		
e.	<i>... that parents and other family members could or should be doing that they're not already doing?</i>		
f.	<i>... that persons with disabilities could or should be doing that they're not already doing?</i>		

Comments: _____
