

Perspectives on Disability in Three Cultural Communities: Downtown Toronto, Canada

*A community-based, participatory research project
funded by the Canadian Centre on Disability Studies*

Scadding Court Community Centre (SCCC) in downtown Toronto has a history of serving a culturally diverse community and plans to increase its services for people living with disabilities. To accommodate the Centre's various activities successfully, there must be an understanding of how those activities relate to and can support each other. Accessible, useful information about disability and culture is however, limited. Perspectives on Disability generated local information for use by the Centre and at the same time contributes to the small body of literature on the intersection of disability and culture currently available to service providers.

The Project

Perspectives on Disability was designed to:

1. Learn about the perceptions of disability in the Chinese, Portuguese and Vietnamese communities in Scadding Court Community Centre's catchment area;
2. Identify barriers to the acceptance and success of a community centre that integrates people with disabilities in the Scadding Court community; and
3. Identify a minimum of five concrete strategies to reduce these barriers.

The Project Team

Perspectives on Disability was directed by a Project Committee of disabled and non-disabled representatives from the cultural groups studied. Members knew little about research and the process was facilitated by a Scadding Court staff member with research experience. The participatory nature of the project was further enhanced through identification and training of community members as focus group facilitators, note-takers and translators and through dialogue with key community contacts during the data analysis stage.

Definition of Disability

The definition of disability developed by the Committee has become SCCC's official definition of disability:

A state, either temporary or permanent, that results in difficulty performing everyday activities within a reasonable time and/or with a reasonable amount of effort. Such a condition or state may be mental, physical, social, emotional, intellectual, or of a nature that is defined by the individual affected.

The Research Design

This study gathered information in three ways:

1) Questionnaire: A questionnaire was developed and translated into Chinese, Vietnamese and Portuguese. 91 questionnaires were received: 29 Chinese, 31 Vietnamese and 31 Portuguese, most from adult women under age 65, with low participation by men and youth. Most respondents were born outside of Canada - in China (93%), Vietnam (97%), Portugal (32%) and Brazil (42%). "Portuguese" responses are from both the Portuguese and Brazilian cultures, which affects the strength of the information on this group but still provides a sense of local Portuguese-speaking community opinion on disability.

- A strong fear of people with mental illness was consistently articulated by all groups and is supported by the information reviewed and community consultation. Generational differences in perceptions of disability observed, with younger generations being more positive, may not apply to mental illness.
- Vietnamese participants showed a strong emotional reaction to disability, expressing empathy versus the sympathy expressed by the other groups. They were however, least comfortable with integrated programming, raising questions about links between their emotional response, attitudes and behaviours.
- Vietnamese participants had the lowest rates of formal education but were most likely to consider disability a "big picture" issue affected by health care, occupational health and safety, politics, economics and other factors. This reflects a holistic perspective not seen in the other groups.
- Perspectives on disability can change simply by "seeing" how disabled people live and are treated in Canada. This suggests that strategies to promote inclusion could build on an image already being projected.

Lack of knowledge, experience and interaction with people with disabilities is common to all three groups and requires targeted outreach, education and interaction opportunities, with a specific focus on mental illness. Unique cultural barriers to inclusion exist also that need to be addressed individually. Scadding Court Community Centre also discovered that it needs to promote its existing programs for people with disabilities in the local community. Finally, the study provided information on how best to reach the ethno-cultural groups studied, making the application of the study findings easier and more likely to be effective.

Where do we go from here?

This study succeeded in shedding light on the perceptions of disability in all three groups. A sense of community perspectives about disability and culturally specific information about perspectives, challenges and opportunities will enable SCCC to tailor its activities so as to promote and enhance the successful inclusion of people with disabilities.

All three groups identified a generally negative perception of disability, lack of knowledge and fear/discomfort about interacting with people with disabilities and fear of harm from people with mental illness as factors that keep their communities from interacting with people who have disabilities. Some community members may also have concerns about the implications for services available to the rest of the community and/or feel that there are already enough services for people with disabilities. Strategies that Scadding Court will apply to address these barriers can be summarized as follows:

EDUCATION

1. Educate the local community about disability using the approaches and formats suggested by the groups studied.
2. Educate the community about mental illness specifically.

INTERACTION

1. Provide opportunities for interaction between people of differing levels of ability through employment, programming, volunteering, Board and Committee membership, etc...

PROMOTION

1. Apply and promote the broad definition of disability developed by this project.
2. Apply a definition of diversity that explicitly includes level of ability, race and culture and other factors.
3. Promote Scadding Court's programs for people living with disabilities.

A detailed report on this project is available at www.scaddingcourt.org

2) Focus Groups: Two focus groups were held per language group. Chinese participants were Mandarin-speaking, mainly female and from a range of age groups. Thirteen people, most women, participated in two Vietnamese groups. Portuguese groups included Portuguese and some Brazilian women, aged 20-60 years.

3) Literature Review: Rather than conduct a formal, academic literature review, the Committee reviewed information that was easily accessible to service providers, as this reflected the intent of the study and highlight the issue of access to information as well as its content. For each of the ethno-cultural groups studied, it was discovered that relatively little information was available. A few key documents developed for service providers in the United States and Australia were identified, however, with the exception of one report on the Portuguese community in Toronto, no such information was readily available from Canadian sources.

Perspectives on Disability Among Chinese Participants

What is disability and how do people react to it?

- A "disadvantage", "deficit", "disease" and "bad luck" due mainly to genetics, accidents and illness.
- Something that affects families and is linked with prejudice, shame, punishment and burden.
- Something that most participants personally have little contact with.
- 69% of questionnaire participants reported feeling comfortable in the presence of a person with a disability but most focus group participants reported the opposite, using words like "upset", "discomfort", "fearful" and "insecure". Sympathy and feelings of personal luck were also expressed.

Disability in Canada

- Most believe that there is much government support for the disabled in Canada, know little about this support and some expressed concerned about potential abuse of this support.
- Just over half of questionnaire and all focus group participants said that their views on disability have become more positive since coming to Canada.

Disability and the Community

- Focus group discussions suggest concern about children participating in integrated programs.
- Most support an expansion of SCCC but some concern about possible service reductions and "congregation" of disabled people (likely referring to people with mental illness).
- Community may not want to interact with disabled people due to difficulty, not knowing how, prejudice, boredom and lack of desire, interest, knowledge, understanding, and patience.
- Suggest education and interaction: pamphlets, flyers, workshops, posters as ways to provide information.

Perspectives on Disability Among Vietnamese Participants

What is disability and how do people react to it?

- Disability is a mainly physical, sometimes mental condition, which can include addiction.
- Described as "bad luck", "disease", "abnormal", "unhealthy", "a flaw" or "a curse on the family" but it can also be a "blessed talent" and mean determination.
- In Vietnam the disabled get no government support, have no rights, are ignored and ridiculed.
- Disability is mainly due to physical, genetic and spiritual factors but focus groups also identified war, poor health care, few workplace safety laws, poverty and bad living conditions.
- 55% of questionnaire respondents reported feeling comfortable with a disabled person, but focus groups reported feeling awkward, insecure and fearful of offending the disabled person.

Disability in Canada

- Most participants felt that Canada provides much government support for disabled people.
- Younger participants knew more about specific services available and were more likely to report becoming more positive about disability since coming to Canada.

- Most people were open to participating in programs that include people with disabilities but reasons varied. Young people emphasized equal rights while seniors said that they would do so to keep people with disabilities from feeling lonely and to raise their spirits.

Disability and the Community

- All participants supported the expansion of SCCC programming for people with disabilities.
- Community may not want to interact with people with disabilities due to fear, lack of interest, empathy and understanding, boredom and not knowing how to interact.
- Information, education, and interaction through conversation and consultation with experts recommended.

Perspectives on Disability Among Portuguese-speaking Participants

What is disability and how do people react to it?

- Portuguese and Brazilian cultures consider disability a "disease", a "deficit", a "difference" and a source of discomfort but people with disabilities can also learn and be smart and strong.
- Portuguese culture has sympathy but fear and mystery about disability exists, especially mental illness.
- Seniors saw sources of disability as spiritual, genetic, accidents, "nerves" or maternal factors.
- Questionnaire answers emphasized physical origins, followed by genetic and emotional.
- People living with disabilities are accepted by their families but are considered a burden.
- Many people reported feeling comfortable around people with disabilities, with Portuguese participants (mainly seniors) feeling less positive than participants from Brazil, citing fear, sadness and nervousness.

Disability in Canada

- 61% of questionnaire respondents felt that Canada offers enough services for people with disabilities and focus group discussion characterized service levels as adequate, not high.
- 25% of respondents and approximately half of focus group participants reported a more positive perspective on disability since coming to Canada. Reasons are government support, better medical services and that Canada is seen to be a more understanding place.

Disability and the Community

- Overall, reactions to the inclusion of people with disability in programming were positive.
- Most said that it would not be a factor in choosing a program - that "anything is fine".
- Unanimous support was expressed for SCCC expansion.
- Community may avoid interacting with disabled people due to lack of knowledge, patience, understanding and respect. They also feel fear, shame, pity, discomfort and do not know how to interact.
- In the Portuguese community, disability is addressed by the family but not by the community.
- Suggestions were providing information on disabilities and the rights of the disabled, dialogue and participation in programs that include people with disabilities.

KEY FINDINGS

- A generally negative perception and stigmatization of disability. The only group to consistently identify positive aspects of disability was the Portuguese-speaking group, which also reported the highest levels of interaction, comfort with and acceptance of people with disabilities.
- Conceptual or theoretical questions (eg. origin of disability in culture of origin) resulted in more negative responses than practical questions (eg. program participation).
- Questionnaire responses were generally more positive than those given in focus groups.
- Chinese and Vietnamese definitions of disability emphasized the physical while the Portuguese saw mental/intellectual capacity as a major aspect of disability.