

“Unlocking the Possible”

A Case for Inclusion

Unlocking the Possible Forum Report
Fort Erie, ON
By Jennifer Hoyle M.A.

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Executive Summary

In 2003, the Community of Fort Erie completed a Social Capital study. Social capital refers to how people in the community form connections, build relationships and social networks with others to achieve goals of common and mutual benefit (Kilty 2004, p.5). It includes aspects of trust, reciprocity, a sense of belonging and inclusion in civic activities, such as town hall meetings, working on the PTA, working on boards of directors, attending grand openings, attending public rally's etc. (Kilty, 2004, p.5).

The intent of the social capital study was to measure the degree to which citizens are able to experience meaningful, trustworthy, participation in civic activities as this affects the social capital of a community. The study did not offer much baseline information about persons with disabilities in Fort Erie, as it did not collect any specific information about people with disabilities within the community.

To further investigate the degree of social capital in Fort Erie, several committees were developed under the Community Health and Wellness group. The Youth Committee under this wellness group conducted the Health of Fort Erie Youth Study, with the help of Brock University. It indicated that young people in Fort Erie were concerned that their peers with mental and physical disabilities were not able to gather with them and enjoy the same social activities. This was especially true after the young person left school, often leaving the young person with a disability socially isolated at home. At the same time as the results from this study were being reviewed, several caregivers and adults with disabilities, from the Fort Erie community expressed similar concerns as those identified by the Youth Committee of the Fort Erie Community Health and Wellness committee.

Persons with disabilities have been defined in the literature as a uniform group of people who have similar defining qualities, implying they are separate and distinct from those without disabilities. Therefore, it becomes difficult to see any similarities they may have with other citizens. As a result, the differences rather than the commonalities between people become the focus of accommodating persons with disabilities in the community.

Literature on persons with disabilities in society, also suggests that one must consider the experiences of the body and the environment when looking at social inclusion models, as the physical body and its movement within the environment may affect the degree to which one is able to be included in community activities.

Based on this information, the information from the Youth study and from citizens with disabilities, it would be fair to suggest that persons with disabilities in the Fort Erie community may experience limited opportunities for social inclusion in the civic activities of their communities. This would then limit their opportunities to contribute to the development of the social capital of the community, and diminish the potential within their community.

A group of community members, particularly interested in this social inclusion, wanted to facilitate the involvement of people with disabilities, in the development of Fort Erie. This group began to meet on a regular basis in February 2004. To work toward this inclusive concept, they planned a forum and called it "Unlocking the Possible". The idea was to gather baseline of information about people with disabilities and the scope of their participation in the community. The information could be used to develop a socially inclusive plan of action. The forum was held at the Fort Erie Leisureplex, on Nov. 23, 2004 for four hours (from 10 a.m. to 2 p.m.) in the afternoon.

Results from the forum indicate that the degree to which citizens with disabilities in Fort Erie felt isolated and/or included was dependent upon the individual lived experiences of their bodies. It was also dependent on how the term “access” was defined. For the participants this meant access to the physical environment, to time, to information, to services and to social networking opportunities. Past definitions of access have also been based on the norm of what it is to be “able”, but this study reveals that the norm around a fixed definition of ability is a misleading. Ability changes over the course of a person’s lifetime depending upon time in life, the situation, and the person’s frame of reference at the time.

Then the question becomes, if all citizens in Fort Erie are able or unable at differing points in their lives, how can the contributions of each citizen be captivated while living in this community. The participants shared the knowledge that comes from experiencing life with barriers to ability. These experiences inform the two main recommendations, which emerged from this forum, for the Town of Fort Erie.

1. Development of a Universal Policy on Inclusion

Community leaders of Fort Erie make a commitment to inclusion practices, through the development of a universal policy on inclusion. This policy would relate to any activity that encourages civic engagement by its citizens, including universal design practices and principles.

2. Development of a Planning Process with inclusive procedures and practices

Once a concrete policy is in place, stating that the community is committed to being inclusive in civic practices, then, the planning process can begin. People who will be using the design need to be involved through all stages (from the beginning to the end) of this process. It should include a review of the Key Features of Inclusive Community Activities, outlined in this report, by the participants in this study.

Literature Review

Background

In 2003, the Community of Fort Erie completed a Social Capital study. Social capital refers to the manner in which people in the community form connections, build relationships and social networks with others to achieve goals of common and mutual benefit (Kilty 2004, p.5). It incorporates aspects of trust, reciprocity, a sense of belonging and inclusion in civic activities (Kilty, 2004, p.5). Civic activities include town hall meetings, working on the PTA, working on boards of directors, attending grand openings, attending public rally's etc. To engender the social trust and encourage coordination among citizens working toward a desired goal, there needs to be an easy flow of communication among participants. If these trustworthy social settings are not nurtured, then social capital will not grow (Kilty, 2004, p.8). In other words, the degree to which citizens are able to experience meaningful, trustworthy, participation in civic activities either increase or decrease the social capital of a community

The intent of the social capital study was to measure the dimensions of social capital in Fort Erie and develop a baseline from which to develop or enhance Social Capital in the Town of Fort Erie. The results indicated that assets of the community of Fort Erie include volunteering, a strong sense of belonging particularly among family and friends, a belief that one can have an impact on decisions to improve the community, as well as a strong measure of reciprocity and trust. Other conclusions from the social capital study suggested that perhaps communication needed to be included as a determinant of social capital (Kilty, 2004, p.11).

This study did not offer much baseline information about persons with disabilities in Fort Erie, as it did not collect any specific information about people with disabilities within the community. In fact, the survey questions regarding close friends and diversity of friends across cultures, religions and socio-economic status did not even offer the option of having a person with a disability as a friend.

To further investigate the degree of social capital in Fort Erie, several committees were developed under the Community Health and Wellness group. The Youth Committee under this wellness group conducted the Health of Erie Youth Study, which was completed by Professor Heather Kilty of Brock University. It indicated that young people in Fort Erie were concerned that their peers with mental and physical disabilities were not able to gather with them and enjoy the same social activities. Resources, including educational opportunities, appeared to be abruptly withdrawn after the young person left school, leaving the young person with a disability socially isolated at home (Mindorff, May 2004).

At the same time, as the results from this study were being reviewed, several caregivers and adults with disabilities from the Fort Erie community expressed similar concerns as those identified by the Youth Committee of the Fort Erie Community Health and Wellness committee.

These trends are congruent with research findings. Catherine Frazee, in her work on youth with disabilities, found that patronizing stereotypes that portray these youth as inferior, and encourage continual low expectations of their abilities. Segregated social institutions then become the "unconsciously justified" means for accommodating the differences experienced by youth with disabilities in the community (Frazee, 2003).

To better understand this phenomenon, a review of the literature on disability is needed.

Ability and Social Inclusion: A Review of the Literature

Disability has been viewed through several models (i.e. Biomedical, Social Construction, Economic, Equality Rights) and the thought processes behind each of these models incorporates strategies to accommodate disability within society.

The Biomedical model sees disability mainly in terms of a bodily impairment (Nixon, 1984, p.163). So the individual with the disability is viewed as a person who is sick, misfortunate, to be pitied, in need of help and specialized care (Bickenbach, 1993, Morris, 1989). As a result, people become treated by medical, specialized and segregated care.

Viewing disability in mainly medical model terms advances notions of social marginalization (Kretzmann & McKnight, 1993). People who have been labelled as disabled are often isolated from mainstream society because it is believed that they would be better served with “specially trained professionals” (Kretzmann, John P. & McKnight, John L., 1993). This is a “service-based” way of approaching disability where caring for deficiencies becomes the sole focus for treating individuals rather than recognizing their talents and capacities to contribute to society. Surrounding people with specially trained individuals alone can lead to their isolation (Kretzmann & McKnight, 1993).

The socially constructed model of disability is the result of deep-seated beliefs of what it is to be normal. These beliefs are embedded in our social consciousness and are used to legitimize social policies (Oliver, 1990). This suggests that there are standards of normality & those who live outside of these standards become disadvantaged (Oliver, 1990). Persons with disability become stereotyped and labelled according to what is considered as “normal”.

The emotional barriers between persons with disabilities and fellow citizens proved to be a big obstacle for many. Stereotypes about people with disabilities were harmful because they create attitudinal divisions amongst people. Ron Mace, late founder of The Centre for Universal Design, talked about the danger of stereotypes.

“We discount people who are less than what we popularly consider to be “normal”. To be ‘normal’ is to be perfect, capable, competent, and Independent. Unfortunately, designers in our society also mistakenly assume that everyone fits this definition of ‘normal’. This just is not the case.” (in Waterloo Region Trends Research Project, 2001, p.1)

These attitudes become ingrained in the development and operation of our social structures. Therefore, buildings & facilities that facilitate social activities are not always accessible (i.e. restaurants/shops). This limits options for social networking.

Such labels encourage focusing on what is different rather than on what is the same among people. Labels tend to mislead our belief systems so that persons with disabilities, experiencing the same human qualities as everyone else (i.e. needs for dignity, friendship, pleasures, hope for the future and a useful place within the community) are often overlooked (Kretzmann & McKnight, 1993). When persons with disabilities are seen as being disadvantaged by negative stereotypes that label & stigmatize them, this in turn isolates them in society (Bickenbach, 1993). The problem with the social construction model of disability is that it locates disablement issues solely within society and neglects issues of the body.

The economic model of disability considers accommodation for disabilities as a social obligation, a financial issue, and social policies are put in place to help. Under this model, the goal is to make persons with disabilities more employable (Bickenbach, 1993). The economic model tries to ensure the inclusion of persons with disabilities in the economic framework of society through policies. The belief is that this will change the experience of disability within the social context, but it neglects to recognize that this does not change the impairment or the process of stigmatization experienced by persons with limited functional abilities.

The Equality Rights model works further toward inclusion. Here, persons with disabilities are ensured equality of treatment because, as a Canadian citizen, they are entitled to the same rights under the law due to the Canadian Charter of Rights and Freedoms. This belief was the motivation behind disability rights groups. The concern here is that individual experiences of disability may be lost (Morris, 1993). Even though people with disabilities may have experiences of discrimination in common, the individual experiences of their bodies are diverse & individual. This must be taken into consideration (Wendell, 1989). Aspects of the medical model of disability need to be considered or the lived realities of the physical experiences of disability (i.e. living with pain & physical limitation) are denied (Morris, 1993).

In all of the above models, persons with disabilities have been defined as a uniform group of people, who have similar defining qualities, that differentiates them from those without disabilities. This sets up an “us & them” situation that suggesting that persons with disabilities are separate and distinct from those without disabilities. Therefore, it becomes difficult to see any similarities. It is the differences rather than the commonalities of lived experiences that become the focus for social accommodation. On the other hand, in inclusive settings, people with disabilities have the opportunity to discredit the negative stereotypes and challenge the notion of disabled and non-disabled that “reinforce the boundaries between sameness and difference” (Hoyle & White, 1999).

From a community capacity point of view, this situation of separateness disengages persons with disabilities from participating and being involved in the growth of their community.

“A true community is only able to grow and strengthen itself by including all of its members and finding room for them to develop their capacities within its own pattern of growth”. (Kretzmann, John P. & McKnight, John L., 1993)

Social inclusion models for person with disabilities, take this into consideration. The Laidlaw Foundation talks about cornerstones of social inclusion in their Working Paper Series entitled, Perspectives on Social Inclusion. Social inclusion calls for the assurance that all community members can expect to be valued, respected and contribute to the community as a whole. (Laidlaw Foundation, 2002-2003). Persons with disabilities need opportunities to interact with non-disabled persons so that they can connect on a human level, which emphasizes their similarities with other citizens rather than differences (Hoyle, 1996).

Kretzmann & McKnight (1993) supports this by suggesting that communities need human capacity skills such as individual abilities & skills, hospitality, compassion, friendship, happiness and inspiration to build a community, by increasing the social capital of the community. They go on to say that these are skills and talents that people with disabilities have to offer. Social inclusion goes beyond the barriers that exist for diverse groups of people in the community to recognizing “the commonality of lived experiences and aspirations among all people” living in a community (Laidlaw Foundation, 2002-2003).

From the literature, it can also be concluded that one must consider the experiences of the body and the environment when looking at social inclusion models, as the physical body may affect the degree to which one is able to be included in community activities. Most models for disability have neglected the fact that the body has a biological component that changes physically according to its relationship with the environment (social & physical) & itself (Hoyle, 1996).

A group of community members, particularly interested in this social inclusion, wanted to facilitate the involvement of people with disabilities, in the development of the Fort Erie community. Here, skills and abilities would be valued, recognized and utilized in the creation of an inclusive community where the capacities of all members would be valued. Therefore, the purpose of the Unlocking the Possible forum was to gather baseline information upon which a socially inclusive plan of action could be developed, that would involve all community members in the civic activities of Greater Fort Erie community. The goal was to describe the broader picture of people with disabilities, living in the community and the scope of their participation in the community. It was also important to amplify the value of the qualities and civic contributions individuals living with disabilities brought to the community.

Possible Hypothesis

After reviewing the literature and the background information, a suggestion for a possible hypothesis is:

Persons with disabilities in the Fort Erie community experience limited opportunities for social inclusion in the civic activities of their communities and therefore experience limited opportunities to contribute to the development of the social capital of their community.

Methodology

Type of Study.

This qualitative study, conducted in a forum setting was to gather information about the inclusion of people with disabilities in the Greater Fort Erie community. Participants were divided into four focus groups composed of persons with disabilities, caregivers and service providers.

Participants

Anyone, with a disability, aged 16 and over, who wanted to participate in their community, or a person who cared for someone with a disability and/or provided service to people with disabilities in Greater Fort Erie were invited to attend. The number of participants was limited to 40 people, on a first come, first serve basis. This was made clear in the invitation and the follow-up phone call.

The first step in this research was to develop a small group of people who acted as the steering committee for the forum. There were 6 people on this committee including persons with disabilities, caregivers and service providers. Since this was a forum looking at inclusion, it was important to the committee that all aspects of the planning be inclusive.

A list of addresses of service providers who provided varying services to people with disabilities in the Greater Fort Erie area was developed, as well as a list of people with disabilities and caregivers. People from these groups were invited to be community partners in the planning and operation of the forum. There were 9 community organization partners, one university, 3 community volunteers, and one business.

The registration form (see Appendix 1) was sent to all the names on the list and all the partners. The registration asked for dietary, mobility and communication concerns to ensure that the needs of the participants could be anticipated in the planning process. Recipients of the letters were asked to share the registration information with anyone who may be interested in attending the forum.

To ensure citizens with disabilities in the community had access to information about the forum, additional strategies were put in place. Several modes of communication were used in an effort to contact as many people as possible including an ad in the newspaper, word of mouth, the Community Health and Wellness website and interested parties could receive registration via e-mail through the different organization partners.

Follow-up, reminder phone calls were made to ensure that all those contacted would have full understanding of the purpose of the day, the time, place, the options available to them if they were unable to attend. Several participants in the forum stated that the follow-up reminder call was very instrumental in their desire and decision to attend.

Purpose of Forum

The purpose of the Unlocking the Possible forum was to gather baseline of information upon which a socially inclusive plan of action could be developed, which would include all community members in the civic activities of the Fort Erie community. The forum would help to describe the broader picture of people with disabilities, living in the community and the scope of their participation in the community. It was also important to amplify the value of the qualities and civic contributions individuals living with disabilities bring to the community.

Timelines and Location

The forum was held at the Fort Erie Leisureplex, on Nov. 23, 2004 for four hours (from 10 a.m. to 2 p.m.) in the afternoon (See Appendix 2 for outline of the day). One question was addressed before lunch and the second question was addressed in the afternoon.

Timelines given for the morning and the afternoon session were not rigid as it was important to accommodate the requirements of the participants.

Assistants to Research

The guest speaker was an active participant in the planning of the activities of the day. The guest speaker is an expert in disability issues and inclusion. Along with the guest speaker for the day, guidelines for the facilitators were developed to ensure all participants had an opportunity to speak.

Forum guidelines

Each focus group had one facilitator, one note taker and one flip chart recorder. Each of these individuals was made aware of the process for the day.

All facilitators were experienced and trained to facilitate groups. To control for objectivity, the goal was to use facilitators from outside the Fort Erie community. Three were from outside the Fort Erie community. Two facilitators self disclosed that they personally had disabilities. The facilitators were invited to take part in the planning of agenda and proceedings of the day. Their role was to help participants keep the focus of the day in mind and they were required to have the skills to bring the members of the group back to this focus. In this way, they could take people beyond the obvious barriers of disabilities.

This was accomplished through questions that encouraged people to look beyond the obvious. Michael Quinn Patton, in his work entitled Qualitative Evaluation and Research Methods (1990), suggests several kinds of questions that will illicit quality responses when doing research. These include:

1. Experience/behaviour questions that ask about what people do or have done, descriptions, their behaviours & activities.
2. Feeling questions that help us look at how people respond emotionally to their experiences and thoughts. Quinn Patton (1990) believes that “feeling” happens inside. Feelings are natural and spontaneous and should not be confused with how someone “thinks” about a situation.
3. Knowledge questions encourage participants to answer what they understand to be factual information. It includes what they know is fact rather than opinions or feelings.
4. Sensory questions relate to what people see, hear, touch, smell & taste. Respondents are encouraged to describe what they are physically sensing. These questions “capture the experience of the senses” (Quinn Patton, 1990, p.293).
5. Background/demographic questions are those that identify characteristics of the respondents so that they can be located in relation to other people (i.e. person with or without a disability, age etc.)

Each facilitator was given a package at the beginning of the day, with all of the questions for the day and points to keep the participants on track (See Appendix 3). One of the packages was modified to accommodate for one of the facilitator’s visual requirements. Each package also included the questions for the day in large print for the visually impaired and questions for participants to give to anyone else that may be interested in giving their input but were unable to attend. (Appendix 4)

The flip chart recorders recorded the main points that rose out of each group's discussion so that it would be visible to each member of the group and later shared with the larger group.

Note takers were to take more detailed notes of specifics given by participants. This information was added to the data from the flip chart recorders and was included in this report.

A video was taken of the events and activities of the day to possibly be used as a template for other communities who may be interested in doing some community planning around social inclusion.

The day was planned with a focus on inclusion and capacity building of persons with disabilities. For this reason, an inclusive scenario was given concerning an event that anyone in the community would be able to access. To ensure that participants focused on inclusion, they were encouraged to make the assumption that they were able to get to event and that it was a community event open to all members of the community. Therefore, it would be perfectly natural for them to attend and express their ideas.

After the morning session, the four groups reported on the responses to the morning question and scenario given by their respective groups, in front of the larger group. At the same time trained research volunteers wrote main points that emerged from the responses on a flip chart. These responses were placed on the wall at the back of the building. Each participant was given four stickers dots and were asked, during the lunch break, to place their stickers on the points that were most important to them.

After lunch, while the groups were answering the second question, trained researchers used the "dot pages" to sum up the information given in the morning and develop the key areas of importance as described by the participants. This information was presented on overhead and verbally to the participants at the end of the day.

The reality of living with a disability could not be ignored as these realities have an impact on the extent to which people with disabilities can take part in community activities. Therefore, the afternoon question asked about the experience of living with a disability in Fort Erie.

Consent & Confidentiality

A consent form, for the video taping of the forum, was attached to the registration form (See Appendix 1). To ensure confidentiality of the statements given at the forum, no names were given in the report.

Scope & Limitations

Recipients of the registration were given the option to be contacted by someone from the committee for their input if they were unable to attend. Although the participants were limited to 40 people, it was indicated that there was a possibility for another forum if there was substantial interest.

Notification time regarding the forum was short (one to two weeks) because funding options, that allowed the forum to take place, were delayed. This could account for the fact that a waiting list for another forum did not develop.

At the end of the day each participant was to receive a copy of the summary from the morning session, but there were some technological problems, which made it impossible. Therefore, the summary was presented verbally and participants were told they would have access to this information at a later date. They would also be notified when the report was completed.

An LCD projector was made available for persons who needed assistance with augmentative communication. Two assistants were available to assist people with their personal care needs and there were people to help participants fill in the evaluation form.

Compensation & Feedback

Several strategies were used to ensure that participants were given feedback on the events of the day.

1. A summary of the information gathered from the morning session was verbally and visually presented to participants at the end of the day. Forum participants will have access to the written summary of the entire events of the day. The results will be available to participants as well through e-mail and on the Community and Health website.
2. An open invitation was given to forum participants to sign up and be part of a committee that would use the results of the day to start a plan of implementation of social inclusion.
3. The intent is to present the findings and recommendations to the Community Health and Wellness Committee of Fort Erie and Fort Erie Town Council.

At the end of the day, evaluations (see Appendix 5) were given to participants at the forum asking about the experience of the forum, whether or not they felt the day did what it said it would do and questions about whether or not they felt included. There was also the opportunity for people to make comments.

Presentation of the Data

There were forty-eight participants at the forum ranging in ages from 20 to 60 plus. There were a variety of people with differing disabilities (i.e. Brain Injury, Cerebral Palsy, cognitive delays, visual and/or hearing impairment, learning disabilities, to name a few). Fifty-six percent of the participants filled in the evaluation form. The highest percentage of respondents came from the 50 – 59 age cohort (25%) and the lowest percentage of respondents was from the 60+ (4%) categories. Percentages of respondents from age cohorts between 20 and 60 were fairly evenly represented, and 22% of respondents did not leave an age. Of those who completed the evaluation form, 52% stated they were people with disabilities, 18.5% stated they were caregivers and 44% stated they were a service provider for persons with disabilities. Twenty-six percent of the participants identified with more than one category to describe themselves. There were more female (70%) than male (30%) respondents.

Some people left the forum early and did not get the opportunity to complete the evaluation form. Perhaps other reasons for not completing the form could have been because of difficulty with reading it and not being aware that there was assistance available. In retrospect, to receive more completed evaluations, it would have been wise, to state that help was available to complete these forms.

Living with a Disability

The information given by the 48 participants during the afternoon session will be presented first. Data gathered from the afternoon session of the forum related to the day- to-day experience of living with a disability in Fort Erie. The participants were asked:

Tell us about an experience in your day that made you just want to stay home and what would have made a difference. What would have made it a better day?

These questions evoked some discussion about barriers to inclusion. The degree to which citizens with disabilities felt isolated and/or included was dependent on the individual lived experiences of their bodies and their access to the social and physical environment in their communities. Please note: Statements in italics are quotes by participants.

Experiences of the Body

- **Physical Strength and Energy - “*How do we open the door?*”**

The experiences of the body affected whether or not citizens with disabilities could take part in community activities. The physical realities that created barriers to inclusion for participants were:

- Aches and pain
- Limited physical mobility, which made it difficult to get around one’s environment. It took more time to carry out activities in a body that took more time to move. The weather and aches and pains had an impact on this mobility.
- Limited physical strength, which meant that even if someone was able to walk or move around, they could only do it for short periods of time. It also meant that everyday activities, like opening a door, became difficult because of the weight of the door.
- A weaker immune system that made people more susceptible to illnesses dictated where and when one went out in the community.
- Fatigue had an impact on the amount of energy that could be used to carry out activities or carry needed equipment. People expressed tiring easily making minimal effort for activities important at times.

- **Unpredictability** - *“I have good days and bad days”*

The irrepensible, unpredictable behaviours and movements of the body were also cited as barriers to carrying out daily living activities. Energy levels were said to fluxuate for some people and dictated what they could and could not do.

- **Personal Care** - *“(My) caregiver takes on my role as well as their own.”*

Some participants with disabilities had support workers, some had family members, but a concern was expressed about their need to sometimes depend on caregivers. Those who expressed this felt they were draining on the caregivers who helped care for their physical needs.

- **Fear of Ridicule** - *“If I think I’m going to have one (seizure), then I stay home.”*

The emotional affects of living in a sometimes uncontrollable and unpredictable body led to fears around social acceptance which in turn affected one’s desire to be involved in community activities.

The physical limitations of the body affected not only how others defined persons with disability but how the disability defined the day-to-day realities of people with disabilities. All of these experiences of the physical body had an impact on what and how activities could be carried out physically and mentally.

Issues of Access

Barriers to accessibility often overlap so that one part of a lived experience affected another. The Ontarians with Disabilities Act (2001) defines a barrier as:

“...anything that stops a person with a disability from fully taking part in society because of that disability” (Section 2).

According to the Act, barriers include physical barriers, architectural barriers, information or communication barriers, attitudinal barriers, technological barriers and barriers that are created by policies or practices (The Ontarians with Disabilities Act, 2001, Section 2).

Therefore, accessibility doesn’t always mean the same thing for all people, as differences in ability require different accessibility requirements. Understanding this multifaceted concept of access appears to be a key element in the development of any inclusive practice.

Access to Physical Environment

The physical environment has an impact on the isolation and exclusion of citizens with disabilities. Accessing the physical environment requires looking at space in general and then how people would move within that space. There were several reasons given for the lack of mobility within the community including arrangement of space and the present mode of community transportation.

- **Space for Differing Mobility Needs** – *“Leave me a spot at the table.”*

- The utilization of space inside buildings created a number of issues for people.
- The amount of space available was not always sufficient. Washrooms were sited as too small and hallways were not wide enough. Sometimes space was not available for people with mobility devices. In particular, the Leisureplex washrooms were said to need accessible doors.
- The placement of items within a given space created mobility problems. For example, tables that were in the way, paper towels placed a distance from the sink and information that was placed too high for people to read were some of the concerns given.

- The types of devices available for mobility issues were not always helpful. For example, elevators that need a key are difficult for people who have limited mobility and/or strength in their hands and fingers. The fluorescent lighting was given as an issue as well because it prompted seizures for some participants.
- Some buildings and sites in the community did not have any adaptations in place (i.e. ramps). There were often steps into buildings and sites. This made accessing activities difficult.

Although transportation was an issue that was intentionally removed as a barrier in the scenario, it kept reappearing when people spoke of lived experiences. The relationship between persons with disabilities and transportation adds insight to issues of transportation already cited by citizens of the Fort Erie community. Participants acknowledged that transportation was available in their community but they felt it did not appropriately meet their mobility needs for several reasons.

- **Community Mobility Service**

This service presented a number of problems for people with disabilities according to forum participants.

- Some destinations were given priority of service over others. For example services for medical appointments was said to have priority over social activities even though the latter activities were considered to be very important to the health of participants too.
- Participants stated that the community mobility service was not available to all persons with disabilities meaning people with less obvious mobility issues did not have equal access to it.
- The final concern about this service was around the hours of availability. Hours were not seen as flexible and participants felt extending hours of service would make it possible, for example, for people to attend community activities in the evening.

- **Local Transit**

The local transit was not suitable for persons with limited mobility due to the steps onto the bus. Families could not go together to community events by using the transit if one member of the family had mobility problems. This limited its use by forum participants.

- **Personal Transportation**

- Participants who could drive, didn't always own vehicles and therefore modes of community transportation became important.
- Parking - Even if people had their own transportation there were barriers that made access to their environment difficult. Parking was cited as an issue because there was not always enough room for parking and not enough monitoring of parking spots for persons with disabilities.
- Curbs were also said to create difficulties for people getting out of their vehicles.
- Others did not want to use certain methods for transport (i.e. scooters) because the length of time spent traveling on a scooter was physically difficult for them.

- **Present transportation Routes**

Access to mobility meant more than transportation to other attendees of the forum. It included making present transportation routes more accessible.

- There was a lack of benches on recreational paths so people could not stop and rest if needed.
- Weather conditions like snow and ice were cited as issues that kept people from going out. Participants said sidewalks and roads were not clear in the winter and this made it

difficult for them to get around by whatever means they were using for mobility (i.e. by foot, scooter, walker etc.).

Access to Time - “Give us time”

It became obvious from the participants that there are different perceptions of time among members of a community. Issues around time were also given as barriers to access.

- **Daily Routine - “It takes time to plan the day ahead”**

Planning and organizing for physical needs took time. Some examples included:

- It took lots of time to prepare an outing, which included investigating the accessibility of where they were going.
- It took time to get ready in a body that took longer to move.
- The time of day in which an activity took place also affected decisions to take part in activities. As mentioned earlier, a number of participants felt that transportation schedules were not flexible enough. Also, the time of civic meetings were not seen as inclusive (i.e. evening meetings).

One person stated that if the planning and decision making to go out took too much time, she would weigh that against whether or not she thought the activity was worth it.

- **Equipment Use - “Give me time to speak and articulate & chat. I can only talk through this”**

The use of pieces of equipment often took more time to use and it required additional time to think about things before responding.

According to these findings, time constraints were not necessarily associated with a lack of time or too much time, rather they were due to time spent planning and carrying out the activities of daily living.

Access to Information - “It is hard to want to go out because of lack of communication and social skills”

A common barrier given was accessing information about what was happening in the community and having the ability to communicate ideas to others, including decision makers.

- The manner in which messages and information were transmitted appeared to be an issue. For example, people with differing levels of reading ability had difficulty reading written information or notices.
- Others who would be able to attend meetings stated they did not do so because the meetings were too large and intimidating.
- Not everyone could get to meetings or events where decisions were made due to previously mentioned barriers. This limited the ability to add to civic discussions.
- The technological adaptations people needed to listen and communicate at meetings were not available.

Access to Services

Some of the services participants did not feel they had equitable access to included employment, recreation, and healthcare services.

- **Employment Services**

Employment meant independence for many participants and it was felt that they were not reaching their full potential if they could not maintain meaningful employment. Jobs were seen to give value and meaning. Some of the barriers to employment were stated as:

- Poor assessment of job skills and potential. It was important that assessors know individuals and their abilities in order to match them to a job they were capable of doing long term
- Lack of job training and placement opportunities.
- Lack of long-term supportive employment opportunities
- No consistency with programs and employment
- Lack of employment for all ages regardless of disability
- Lack of encouragement to continue a job was not available resulting in people being set up for failure.

- **Recreational Services**

Accessing recreational activities within Fort Erie also presented problems for participants. Reasons given for this included:

- **Money - “Disability dollars don’t go far.”**
 - “No money”. For people receiving disability assistance from the government, their disability assistance didn’t go far. The rent that some people paid was more than what was allotted by disability assistance. This meant there was little of no money left for other activities so people stayed home.
- **Availability - “No where to go”**
 - No Accessible place for physical activity, to work out
 - No movie in the community.
 - No consistency with programs
 - Lack of daily activities for adults/seniors with disabilities.
- Present recreational sites were not considered to be accessible to everyone. Some said Fort Erie needed an accessible gym and equipment at any new and established recreation sites (i.e. YM CA).
- Some felt the attitude by recreational organizations was less than welcoming.
- Lack of staff in residential settings made it difficult for people who needed support, to go out.

- **Health Services - “Doctors assume things (i.e. medical problems) are related to hormones.”**

Accessing health services within the community had its drawbacks as well. It was not only the transportation or limited services that made access difficult. It was also concerns around human resources and the physical site itself.

- Participants felt they were not seen as credible by medical staff. Staff needed to be more understanding.
- Equipment in health care sites was not always accessible either. For example, the examination table was not useable because it was too high for her to get onto.

Access to Social Networking Opportunities

The ability to socialize and communicate with other members of the community was a key component to inclusion for participants. Having the opportunity to engage with others in the community was essential.

- **The Importance of Social connections - “Coffee with a visitor can turn a bad day around.”**

Participants expressed the desire for social connections in their lives and the importance of having a support network. This could mean supported assistance for day-to-day living activities but it was just as important to have “a network of friends”. It was stated clearly by participants that they lacked inclusive social meeting places, activities and groups.

Participants expressed that the attitudes and negative reactions of others were reasons for not being able to be more involved in social activities.

- **Dependent vs. Interdependent - “(I like) being allowed to try before being told I cannot.”**

Participants did not want to be seen as dependent rather, they wanted to be seen as interdependent with other members of the community. Wendell (1989) supports the idea of interdependence by suggesting that “we need to change our social values regarding dependency/independency to recognize the value of dependency on others & being depended upon. This could lead to a “model of reciprocity” so we recognize each other’s need to rely on others, respecting boundaries and asking for help (Hillyer, 1993). Even though Kilty (2004), in her study of Social Capital in Fort Erie, found that there was a high sense of reciprocity in this community, this forum would suggest that person with disabilities in the Fort Erie community are not feeling that same sense of interdependence and reciprocity with other citizens.

- **Low Expectations - “ I will ask if I need help – I am quite capable.”**

Participants felt that others had low expectations of them and were always trying to “correct your life”. They felt the need to prove themselves. In her study on youth with disabilities, Frazee (2003) suggested that low expectations made it difficult for these youth to express their talents and capacities. One participant summed up the negative affects of patronizing attitudes this way.

“I can do lots on my own. Sometimes (they) make me feel like I can’t do anything, when I learned everything on my own. Sometimes I’m treated like a kid and not like an adult. Workers sometimes treat us like a kid. People shouldn’t assume.”

- **Questioning Intelligence - “ I don’t want my intelligence to be underestimated due to disability.”**

Associated with the low expectations of persons with disabilities was the stereotype that disability equals lack of intelligence.

- **Disability vs. Person – “Don’t see me as a disabled person, just as a person.”**

Access was strongly related to perceived notions of difference by others. The problem with perceiving others as different becomes a problem when differences are viewed as less-than or negative. This becomes a potential environment for inequitable behaviour. Participants felt they were identified by their disability and not by their own unique person. They did not want others to focus on what they could not do, rather on what talents they had to offer to the community. In this way, sameness rather than difference could help in creating social supports for them.

Feeling included meant having a sense of belonging in one’s community. Participants indicated that a sense of belonging was not a reality for many of them. When asked what would make them feel included in civic activities they responded as any other citizen might respond:

- *“To feel a part.”*
- *“To know my input mattered and had value.”*
- *“To have a purpose to go to an event.”*
- *“Someone to encourage me to attend.”*
- *“To be seen as competent.”*

In sum, participants wanted to have their specific needs directly related to their disability addressed but not to have their disability define them. They felt they had things in common with other members of the community and wanted that social connection. They did not feel that their opinions were taken seriously or were valued. They wanted the opportunity to try.

Strategies for Inclusion

Several participants at the forum recognized and stated that participating in civic activities, in a meaningful way, was in part the responsibility of a person (regardless of ability) as a citizen of the town, but the experience of living with functional limitations often affected access to these activities. Somehow, individual needs of citizens had to be met within the larger context of their community, without exemplifying differences. In this way, everyone would feel valued and included.

Other communities committed to inclusion (i.e. Waterloo region) have considered Universal Design as part of their strategy for inclusion. This design goes beyond traditional specialized accommodations for people with disabilities to designs and strategies that accommodate not only persons with disabilities but other community members as well.

“ Universal Design is the design of products and environments to be usable by all people to the greatest extent possible, without the need of adaptation or specialized design”
(The Centre for Universal Design, 1997).

Universal Design tries to consider all members of the community regardless of “ability on any one day or at one stage in (our) life”, so that all citizens can have “equal opportunity to participant in a more caring community.” (Waterloo Region Trends Research Project, 2001, p.1).

Data gathered in the morning session of the forum related to inclusion. Participants were given an scenario of an event that would be open to any citizen of the community. It was a town hall meeting regarding a community health center. Then attendees were asked:

What will encourage you to get to the meeting and ensure that your ideas are received and what will keep you from getting your ideas received? What are your ideas?

All of the information received from this question have been categorized into key features to ensure the inclusion of persons with disabilities in civic activities (i.e. town hall meetings, working on PTA’s, working on boards of directors, attending grand openings, attending public rally’s etc.). Although these strategies related to the specific events outlined in the question (i.e. a town hall meeting and a community health centre), the key features could be used as guidelines in planning other inclusive activities in the community. The strategies given by participants embraced the principles of universal design. These principles include:

1. Equitable Use – The design is useful and marketable to any group of users
2. Flexibility in Use – The design accommodates a wide range of individual preferences and abilities.
3. Simple and Intuitive Use – Use of the design is easy to understand, regardless of the user’s experience, knowledge, language skill, or current concentration levels.

4. Perceptible Information – The design communicates necessary information effectively to the user regardless of ambient conditions or the user’s sensory abilities
5. Tolerance of Error – The design minimizes hazards and adverse consequences of accidental or unintended actions
6. Low Physical Effort – The design can be used effectively and comfortably and with minimum of fatigue.
7. Size and Space for Approach and Use – Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user’s body size posture, or mobility.

(Bettye Rose Connell, Mike Jones, Ron Mace, Jim Mueller, Abir Mullick, Elaine Ostroff, Jon Sanford, Ed Steinfeld, Molly Story, & Gregg Vanderheiden for The Centre for Universal Design, 1997)

Three distinct time frames were identified within these key features of inclusive community activities in order for citizens to be able to participate: before, during and after the event. Each of these time frames had suggestions associated with them (See Appendix 6).

Key Features of Inclusive Community Activities

Before

“If you want us there make sure we know we are invited.”

It was clearly expressed that everyone in the community (i.e. “*young, old, working people, different cultures*”) needed to be encouraged to attend civic events and the way to accomplish this was to have more public notice. The following were suggestions given to ensure that this would occur.

1. Multi-media / multi-sensory - “*Say it three times, three different ways.*”

Use different means to give advanced notice because people access information through different means and senses.

- Mail information to stakeholders.
- Place notices in local newspapers that go to everyone (i.e. The Shopper)
- Use radio and community T.V.- public interest spots do not cost money
- Flyers placed in common places visited by citizens of the community like grocery stores, post office because “*not everyone reads the paper*”.
- Use clear language when advertising through written material so everyone can understand it. Use pictures and large print and watch the font.
- Use technological formats for advertizing- This could include email, fax and websites. It was suggested that the Fort Erie web page would help promote community events to everyone in Fort Erie including different cultures).
- Networking with other community members.
 - Community organizations that people are involved in need to get involved
 - Word of mouth
 - Personal contact through phone calls.

2. Lots of prior notice - *“Let me know what is happening.”*

- Advanced notice offers opportunity to plan ahead for persons attending meetings and events.
- Have pre-registration for meeting or event.

3. Reminders

- Network of citizens need to be utilized to get people out and involved, *“like meeting today.”* Many participants felt that the follow-up phone call for the forum was important to them and their attendance that day.
- Be given the opportunity to make an appointment to give one’s input if unable to attend

During

“Once we are there, show us you are happy we made it!”

1. One Stop Shopping for services

It was felt that all components of an event or activity should be centralized and integrated in one location so they could work together effectively. (Many of the following suggestions are related specifically to a Community Health Centre in Fort Erie but could be related other community activities.)

- Centralize professional services in one location so services are not fragmented and all are within the community - Something in Ridgeway was suggested
- Co-operation between local and regional services
- Co-operation between regions
- Provide space for service providers, whose home base is not in Fort Erie, to meet with clients, host service and/or give presentations
- Be proactive in working together with agencies of specific disabilities.
- Have trained professionals - Different types of Health professionals i.e. OT, PT, nurse practitioner, staff for survivors of sexual abuse, *“Doctors with the backgrounds to address our issues.”* (i.e. expertise, resources, references)
- There was a big request for Mental Health services to be available in the community as “opposed to larger hospitals”
 - Adult & children’s mental health office, resources, support
 - Walk-in counselling would help with waiting for service
 - Access to psychiatric help for children

2. Person First Policies and Treatment - *“Meeting code doesn’t mean it meets the needs.”*

Inclusion in any meeting or event requires policies that support and encourage the equitable treatment of citizens. Suggestions for *“person first”* treatment included ideas for policy and treatment by human resource staff.

- Standardize Disability Act requirements within the community. There was a suggestion that businesses be required to meet accessibility requirements as stated in the Ontario with Disabilities Act (ODA), 2001 which require “that the level of accessibility for government buildings is at least as good as or better than the level of accessibility required by the Building Code Act, 1992 (Section 4.2). The ODA (2001) also states that accessibility plans

in municipalities consider ways to remove barriers to people with disabilities through municipal by-laws and their policies, programs, practices and services (Section 11).

- Staff should be educated and know about many kinds of disabilities, “*otherwise there can be a communication barrier right out front*”.
- Staff members need to be sensitized to individual needs of people as human beings in general.
- With regard to a community health centre, make it possible to only have to share personal information once and then make it possible to have this information shared by other services.

3. Universal Instructional Design for maximum opportunities to participate – “*I want to say something.*”

Participants expressed the importance of having the opportunity to be able to understand what is happening at community events as well as give their input. Universal instructional design means designing instruction, materials and content so that everyone, regardless of learning style, can have equal access to learning, not just equal access to information (Universal Design for Learning, Ohio State University Partnership Grant, 2004). Suggestions were given by participants to ensure equal access to learning, information, and participation at a town hall meeting and/or community health centre. These included:

- An open forum
- A microphone to help increase the volume of the voice of participants.
- Be aware of communication requirements of participants so adjustments can be made in the presentation of material and gathering of comments
- Use different communication modes
 - Technology available for individual needs – i.e. head phones for meetings, or FM systems available
 - Accessible communication stand with multi-media outlets or seating
 - Availability of translators for people with language barriers or hearing impairments.
 - Slow down the pace for people who need more time to assimilate what is being discussed or to offer suggestions - “*Give me time to speak & articulate. I can only talk through this.*”
 - A signal to let council know someone with communication device wants to speak
 - Use different formats of meetings – i.e. small groups can be more open for people to express themselves and voice opinions without intimidation. - “*A forum like today is less intimidating.*”
- Outreach to those who cannot attend and give their input
 - Send out surveys in an anonymous way.
 - The ability to submit ideas on line.
 - MSN technology to get response from people who cannot get out or are not comfortable
 - Teleconferencing
- Signage in buildings as to what is available
 - A calendar of events and who will be in on certain days and updated calendar of events on website
 - Places for resource information regarding what is available and community resources in general
 - Information services with a phone number to access. If the service cannot be provided then there needs to be an awareness of resources in community and how to contact them. Citizens need to know the proper network to get their needs met (i.e. for assistance with language barrier go to multicultural centre)

- Display poster stating what services are available in buildings.
- Use of colour codes for information
- Consider time of day for meetings and events – i.e. maybe daytime meetings as well as evening meetings

4. Disability Representation at decision level (appointed, advisory, et al.) - “I’m tired of advocating for myself.”

Participants stated they had limited opportunities to take part in community decisions that would have an impact on their lives. There was a sense that they were alone in trying to get their messages to the decision makers who needed to hear them.

According to Waterloo Region Trends, Research Project (2001) which studied Universal Design in the Waterloo Region, it is important that people who will be using a design be involved from the beginning of the planning process. This includes all aspects of the planning process from pamphlets, to buildings, to equipment to structures (p. 14). This is not always the case. Research suggests that often leisure environments are not only designed by decision makers without the input of persons with disabilities but reflect the belief that all persons with disabilities have the same functional abilities as a group and are viewed as a separate social group (Hoyle 1996). This resonates with the notion that special treatment for persons with disabilities is better than equitable treatment for all.

Participants at the forum wanted to feel that they had a part in the decisions making. They expressed having “*experience and knowledge*” that planners could use during planning processes. They wanted the opportunity to share their ideas because such processes would have an impact on their daily living. One suggestion was to have a person with a disability lead focus groups that could be involved in the planning process.

5. Wholistic and Wellness based services (i.e. include more than medical and sport)

Attendees at the forum clearly stated that in the planning of community activities or meetings, there needed to be accommodation for the many aspects affecting the lives and well-being of community members. This required considering issues in a larger context so that quality of life encompassed more than sport and medical options. For example, in planning a community health centre, having more than medical services (i.e. “*gyms, workshops, restaurants, entertainment activities*” etc.) meant more opportunities for community members to be integrated into community. It meant there would be more social opportunities for people to gather. This, in turn, would encourage the easy flow of communication needed for citizens to nurture the growth of social capital in the community. It was suggested that community organizations had an important role in making this happen as pointed out in this statement.

“Community organizations brought people together for (this) forum.”

It was also thought that a community wellness centre could assist in taking on this role. The concentration was on wellness in general. Participants gave suggestions, for more wholistic services to be included in a community health centre.

- Activity groups
- Workshops including Internet & computer
- Social activities
- Stricter regulations about smoking near entrances or else have a separate room for smoking
- First Aid Station

- Accessibility of computers on site for the public to use (i.e. internet). This would encourage base set technology in the community for all.
- Integrated services

6. **Universally Designed Environments – (i.e. colour, directions, physical access etc.)**

Accessibility doesn't always mean accessible to all as each person has different accessibility requirements. More physically accessible places that incorporate elements of universal design, like "increased lighting, more pedestrian traffic and open spaces", are often safer (Waterloo Region Trends Research Project on Universal Design, 2001, p. 11).

- **Environment**

Suggestions for accommodating environments for inclusive civic events included:

- Leave more space. – There is a need for big areas to accommodate different mobility requirements. Wal-Mart was given as a good example or a large meeting room "*like here today*".
 - Standardize space requirements for buildings and sites in the community (i.e. standardize width for hallways & doorways).
 - A need for stabilizing features or something to hold onto for security (i.e. hand rail)
 - Better washrooms accessibility –
 - Washrooms need to be bigger with a larger private room and have more than one big stall
 - Include an adult size change table
 - Bathroom stall doors that close automatically.
 - Include items for left & right handed people
 - Everything on one level
 - Activities and items are close at hand (i.e. in washrooms have sink close to paper towels or hand dryers).
 - Coat hooks instead of hangers
 - Ramps
 - A water fountain
 - Accessible keys at elevators
 - Something to filter environmental noise
 - A quiet room or sound proof room with couches and a place to rest
 - Control humidity on site,
 - Control the scents that affect respiratory issues
 - Stimulation room
 - Music
 - Straws for drinking as not everyone can drink with a cup.
 - Fire alarms that are in clear view and easy to access
 - Use of colour codes to assist in movement around large buildings
 - Lighting – some found florescent lights troublesome
 - Size and height of signs so all can see
- **Accessible Transportation** – Participants suggested transportation does not necessarily need to be specific for a person with a disability if it is planned so that "*people can move together*". Some suggestions around freer mobility within the community included looking at what was available and how it could be made more useable.

- **Parking**
 - A need for two types of parking spots; one for wheelchair users and one for persons with mobility impairments. Wheelchair van users often need more space than those with mobility impairments yet the latter group still needs to be at close proximity to the activity.
 - More enforcement needed to ensure accessible parking spots for those who need them.
 - Change parking bylaws – i.e. Curbs in front of cars for easier access to cars.
 - Better reinforcement of present bylaws
- **Present Community Transportation System**
 - Need community transit with wheelchair access open to anyone to use, then people could travel with other family members and friends. Spending time with these social groups becomes significant when one considers how many family and friend members have a connection to people with disabilities. In a 1997, a poll conducted by Omnitel for the Ontarians with Disabilities Act Committee, found that 77% of Canadians stated they interact regularly or know a family member, a friend or an other person with a disability (as cited in Waterloo Region Trends Research Project, 2001, p. 12).
 - Put bicycle racks on the local transit for people who have trouble walking long distances from bus stop to a particular destination but find riding a bike easier.
 - Notify accessible transportation services of the need for extended hours.
 - Have bus shelters and benches at bus stops, on the Friendship trail, and at local businesses for people who are waiting for transportation and/or need rest stations while walking. Accessible sidewalks are needed everywhere.
 - Ensure clear recreation paths, sidewalks, entrances to community and business buildings in the winter
 - Use sound signals for “Walk” at traffic lights for citizens who have decreased hearing ability or are more visually adept.
 - Ramps into buildings cannot be too steep, as it takes more energy and strength to go up a steep ramp for citizens who have issues with mobility.
 - Have more travel means available (i.e. bikes, scooter)

7. Individual and collective awareness - “I want a place to share common concerns.”- (i.e. My disability and everyone else’s is important)

- Creation of inclusive support circles
- Involve businesses around accessibility issues and sensitivity awareness
- Look beyond the cost of accommodation to how changes in design can be utilized by the larger population. If accommodations meet the requirements of more people it is less costly, more efficient and more inclusive. According to the Waterloo Trends Research Project (2001), universal design may cost more in the short-term but over the long haul it decreases future modifications costs, increases the marketability of the site, increases speed of movement of citizens while decreasing fatigue for everyone. It also increases the social ethics within a community (p.12 & 13).
- Obtain the right expertise regarding accessibility and communications
- Research around differences in gender for different disabilities
- Be allowed to try before being told they cannot
- Services need to be little money or no money

8. Strength based problem solving – “We all need to benefit.”

Participants saw the need for working together to find solutions that would work to benefit all citizens while utilizes the talents and skills of all citizens.

- All citizens need to attend meetings
- A central meeting place where one can voice their opinion without feeling intimidated
- Find alternative ways to gather opinions from community
- Focus on interdependence
- Use the “*experience and knowledge*” of the citizens involved.
- Work together toward goals that will benefit all.

9. Come prepared and focused – “What are the issues being addressed and do I know if it would include me.”

(i.e. be prepared to address the topic of the meeting and/or consultation)

- “*If I can’t participate, then I need to get what I need for myself.*” Several participants stated that each person should take responsibility for their own needs and assume responsibility for oneself. This would be dependent on plenty of notice of upcoming events that a citizen may be interested in so she/he could prepare. It would also be dependent on how accessible needed resources were for someone who could not attend but still wanted to offer his or her input.

10. Alternatives / suggestions must accompany complaints

The barriers described by participants were accompanied by suggestions. Suggestions, not yet discussed, included ways to help with the stereotypes associated with disabilities so that people could experience inclusion in their communities. Eliminating perceptions of difference among people makes it easier to see similarities in human experience. Suggestions included:

- Increase the awareness among and about disability in community so people would be treated fairly (i.e. more community awareness about the full aspect of access).
- Offer empathy and sensitivity awareness activities and workshops.
 - Hands on experience of what it is like to have a disability. People would be put in the position of having a disability (i.e. spend day in wheelchair, wear goggles with Vaseline on them to simulate visual a visual impairment).

After

“Keep us involved and invite us back.”

1. Ongoing contribution to discussion (i.e. multi-media/multi-sensory approaches)

- Opportunities for participants at events to give ideas afterwards, but before decisions are made, in a variety of ways. Perhaps another meeting to allow people to prepare their thoughts before giving their input for the decision making process.
- Ability to submit information over Internet.

2. Resource awareness using multi-media / multi-sensory

- Results and new information could be shared on line.
- Outcomes and results communicated in plain & clear language
- Awareness of community resources

3. Follow-up on implementation and decisions - “We need to know that ideas are followed up on and implemented.”

- Allow opportunity for follow-up on important issues
- Feedback given in a timely manner.
- Results needed after the meetings
- Clear timeline for issues to be addressed – “*more action-less talk*”
- Feedback – give it soon enough
- Clear time lines as to when results available.

Conclusions and Recommendations

Conclusions can be drawn about the lived experience of persons living with disabilities in Fort Erie and conclusions can be drawn about their experience of civic engagement in their community, but this piece of research makes it very clear that these two factors cannot be viewed separately. One impacts the other. People seem to be caught in a quandary. If they can't get out to interact with other citizens due to the experiences of their bodies or issues of access, they cannot build social relationship or use their skills and talents. This makes it difficult for them to contribute to the social capital of the community.

Persons with disabilities in Fort Erie are feeling isolated from their community. This isolation makes it difficult to take part in the activities of the community or become civically engaged.

When marginalized, people are isolated and there is a need to replace isolation by active inclusion (Kretzmann & McKnight, 1993). Through inclusion, friendships and trust can develop, and people feel they are part of the community and the social capital of the community will grow. Persons with disabilities in the Town of Fort Erie do experience marginalization due to perceived and real notions of difference but have a strong desire to increase awareness of their similarities with other citizens of the Town. They have expressed an interest in being actively involved in the civic activities of their community.

Any strategies used to promote inclusion of citizens with disabilities in the Fort Erie community means respecting their lived experiences. This does not necessitate special treatment, just equitable treatment that meets individual needs. Recommendations, by forum participants, to accommodate individual differences incorporate the broader concept of social inclusion of "all" citizens in the community. In the accommodation of sameness of citizens, we can accommodate differences and therefore increase the social capital of our community through the talents and gifts of "all" citizens.

The ideal is for community leaders to "mobilize these gifts and capacities and turn them into valuable assets for community building" (Kretzmann & McKnight, 1993; p.71). Therefore, as leaders in a community, municipal governments have the opportunity to take the lead in ensuring the community is inclusive, thereby increasing its social capital. This small local study supports the notion that enhancing the social capital of Fort Erie can be facilitated through the development and implementation of universal policies, procedures and designs.

Strategies for Civic Engagement

Although the idea of universal design was spear headed by a "disability-focused movement" it has been recognized as a useful design for "all" because it provides choices rather than limitations for citizens wanting to be engaged in their communities. Access to civic activities has been based on the norm of what it is to be "able", but this study reveals that the norm around a fixed definition of ability is misleading. Ability changes over the course of a person's lifetime. Ability is not an either/or situation where one is either able or not able. All people live on a continuum that ranges from very high ability to very low ability where some have more ability in certain areas of their lives than in others (Waterloo Region Trends Research Project, 2001, p. 8). One's ability at any particular time is dependent on their time of life, the time of day, the situation they are in and the environment they are in. Some examples given by the Waterloo Region Trends Research Project on Universal Design (2001) reveal some of these fluxuations in ability.

“...the population will at some point either have a temporary limitation such as a broken leg or other injury, or else have short term difficulties such as: carrying heavy luggage, awkward bags of groceries, or laundry; talking on a cell phone; holding onto an active child; be mentally deep in thought because of a work issue or personal problem; a sore arm from playing tennis; and any number of other things that might limit one’s ability to lift, concentrate, see or focus, move or reach. (p. 10 – 11)”

Ability, described in this manner, encourages citizens of a community to recognize that they are more alike than different, promotes a social environment where citizens naturally work toward common goals that will benefit all. Therefore, this supports the development of social capital in a community.

Universal design requires decision makers, planners, engineers, architects; advocates, project funders, citizens and stakeholders to understand this definition of ability that spans a person’s lifetime. Since it is a design that is useful for citizens in general, due to it’s ease of use and safeness for all, it makes sense to make inclusion of universal policies and designs a common practice in development (Ron Mace, the late founder of Centre for Universal Design as cited in Waterloo Region Trends Research Project on Universal Design (2001). Planners must get beyond the disabled/non-disabled dichotomy & look at how functional (or useful, practical, serviceable) a design, program, activity is for **all** people in general.

Universally designed environments require the implementation of a universal policy to ensure the civic engagement and inclusion of all citizens. Universalizing policies will lead to changes in attitudes and stereotypes that underestimate the actual abilities and physical potential of people with disabilities (Zola, 1989). This promotes inclusive, integrated settings that allow for the opportunity to “debunk negative stereotypes” about people with disabilities (Hoyle & White, as cited in White & Young, 1999).

Recommendations Emerging from the Forum Research

1. Development of a Universal Policy on Inclusion

Community leaders of Fort Erie make a commitment to inclusive practices, through the development of a universal policy on inclusion. This policy would relate to any activity that encourages civic engagement by its citizens, including universal design practices and principles.

2. Development of a Planning Process with inclusive procedures and practices

Once a concrete policy is in place, stating that the community is committed to being inclusive in civic practices, then the planning process can begin. People who will be using the design need to be involved through all stages (from the beginning to the end) of this process. It should include a review of the Key Features of Inclusive Community Activities, outlined in this report, by the participants in this study.

Potential Benefits of this Study

1. Provides community leaders with locally validated information to develop policies creating inclusive environments in the Town of Fort Erie. According to Purdue (2000) strong, transformational leaders with a vision of the neighbourhood are needed as the key points of contact between any new governmental initiatives and the local residents (as cited in Kilty, 2004).

2. Provides specific strategies for community planning activities that can be used to encourage the inclusion of more community members.
3. Adds to the knowledge of persons with disabilities in Fort Erie. The information in this report offers some baseline information on the experience of living with a disability in Fort Erie and suggestions on how to make the community more inclusive.
4. This research offers evidence to support the idea that communication needs to be re-examined as a dimension of social capital. One's ability to have access to communication and one's ability to communicate with others, was not included in the dimensions of social capital in the Fort Erie Social Capital Report (Kilty, 2004), but appears to have a significant amount of importance in the lives of persons with disabilities.
5. Provides information for service providers who support people with disabilities in their daily living practices.
6. Provides the opportunity for participants to be contributors of information that could assist in the planning of more inclusive civic activities within the community.
7. Provides the opportunity to build a group of people who are interested in ensuring inclusion in our community. Zola (1989) states that people with disabilities need to be more politically active so not seen as silent and Bickenbach (1993) believes that people with disabilities need to be more politically active to challenge how society and social structure define disability
8. Provides further development of the theoretical knowledge of the social capital of person's with disabilities in small communities.

Suggestions for Further Research

1. Further investigation into communication and its relevance to social capital and determinants of health.
2. Further investigation into mobilizing gifts and capacities of citizens with differing abilities, which change throughout one's lifetime.

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Register Now for:

Unlocking the Possible

A workshop to discuss the inclusion of people with disabilities in our community and explore the contributions they can bring to the community.



The possibilities are endless!

Wednesday November 24, 2004

10:00 a.m. – 2:00 p.m.

Fort Erie Leisureplex Banquet Hall

This sharing, facilitated workshop is open to all youth and adults with disabilities, and parents, caregivers and professionals who interact with disabled individuals in the community. Thanks to funding from the Town of Fort Erie there is no cost to participate and lunch will be provided. Registration is required by November 21.

For more information please contact the
Head Injury Association of Fort Erie 905-871-7789.

To register or give your input if you are unable to attend please contact HIAFE by email hiafe@becon.org or fax 905-871-7823. Registration forms also available at www.communityhealth.forterie.on.ca

Unlocking the Possible Registration Form
Wednesday November 24, 2004
10:00 a.m. – 2:00 p.m.

PLEASE PRINT (NAME AS YOU WISH IT TO APPEAR ON BADGE)

NAME:

ADDRESS:

CITY: _____ **POSTAL CODE:**

PHONE: _____ **FAX:**

EMAIL:

DIETARY REQUIREMENTS:

COMMUNICATION REQUIREMENTS (e.g. Bliss, Sign Language, etc.):

I WILL BE ACCOMPANIED BY A PERSONAL ATTENDANT: YES NO (please circle one)

PERSONAL ATTENDANT'S NAME:

If transportation to and from the event is required please contact Donna at 905-871-7789 by Nov.21

IMPORTANT NOTICE: Registration is on a first come first served basis and is only available for residents of Fort Erie. Every effort will be made to add individuals to a waiting list should the need arise. Furthermore if there is enough of a demand a second Unlocking the Possible Forum will be announced at a later date for those individuals on the waiting list.

Waiver to be Videoed

I understand there is a videotape being taken of me on November 24, 2004. I hereby assign and authorize the producer Leonas Rackausdas the right (All Rights) in and to such videotape. I also authorize said producer, without limitation, the right to reproduce, copy, exhibit-publish or distribute any such videotape, and waive all rights or claims I may have against your organization and/or any of its Affiliates, Subsidiaries, or Assignees other than as stated in this agreement.

Signature of Participant

Signature of Legal Guardian

Date

**(E)Mail/Fax Completed Registration Forms To: Head Injury Association of Fort Erie 649
Niagara Blvd.**

**Fort Erie, Ontario L2A 3H7 Fax: 905-871-7823
hiafe@becon.org**

Appendix 2

Unlocking the Possible

November 24, 2004

Agenda

Welcome - Catherine Mindorff

Welcome - Councillor Schular

Guest Speaker - Maureen Connolly

Maureen Connolly is a professor of Physical Education & Kinesiology and Director of the Centre for Teaching and Learning and Education Technologies at Brock University where she has been involved in teaching, research and service for the past 14 years. Maureen has been actively involved in disability advocacy for the past 30 years and has been involved in developing meaningful activity programs for persons with disabilities in the Niagara Region.

Group Work

Break

Presentation of Group Work

Lunch

Group Discussion and Planning

Appendix 3

Facilitator's Package

The Scenario

The community of Fort Erie is in the planning phase of building a Community Health Centre (CHC). One of the most important parts of planning a community Health Centre is to ensure by a “Town Hall” meeting that every member of the community has an opportunity to voice their opinion and to contribute ideas and information that will lead to a CHC that meets the specific needs of the community members.

You have some ideas about health services that you think will be valuable and you would like to see that these ideas are noted and received by the CHC planners.

You have a disability (disabilities) that may have kept you from going to a “Town Hall” meeting in the past.

BUT

This time you are bound and determined to get to the meeting and get your ideas across.

Transportation is provided and is not an issue today.

The idea is that every community member should expect to be included in any community activity regardless of his or her abilities.

Appendix 3 continued

Facilitator's Scoop

At one of our early facilitator meetings we drew some group management guidelines.

Codes of Conduct to ensure inclusion:

- Everyone has a chance to say something before anyone speaks twice
- The person who speaks is the chair and when they are finished they pass it on to the next person with their hand up
- Ensure the possibility that others can see (through PowerPoint, hand outs of scenario and questions if needed) the communication of people who use computers to speak
- Anyone not wishing to be videotaped would not be excluded. They would either be put together in a group that would not be taped or we ensure the videographer is aware on the request
- If people drift to the negative re: experiences of poor personal service we will remind them that we can talk about that in the afternoon during the “personal experience” session.

Appendix 4

Questions based on Scenario:

What will encourage you to get to the meeting and ensure that your ideas are received and what will keep you from getting your ideas received.

We need you to help us build a plan for our town to make sure that all “Town Hall” or community meetings are “inclusive”.

Things to think about in answering this question:

1. What needs to happen in our community for your ideas to be received and valued when the town decision makers are making a decision about something in the town? It could be a policy decision or a tax increase or a transportation system plan etc
2. Experience/knowledge
What information or knowledge can you offer our town planners about your experience of living in Fort Erie as a disabled person that might help the planner be more inclusive in their work?
3. Describe the ideal community setting for a town meeting. What would the environment look like. What are we missing here to day and what is working for you.
4. Describe an experience in a community setting where you felt excluded. What emotions surfaced?

Question based on Lived Experience:

Tell us an experience in your day that made you just want to stay home and what would have made a difference. What would have made it a better day?

Please send your answers by December 1st 2004 to:

The Head Injury Association of Fort Erie
649 Niagara Blvd. Fort Erie, ON L2A 3H7

OR fax them to call Fax to 905-871-7832

OR e-mail to hiafe@becon.org

OR call 905-871-7789

Appendix 6

Key Features of Inclusive Community Activities

Results of Morning Session - November 24, 2004

Before:

1. Promotion Blitz-
 - a. Multi-media / multi-sensory
 - b. Lots of prior notice
 - c. Reminders

If you want us there make sure we know we are invited.

During: (meetings and provision of health related services)

1. One Stop Shopping for services
 - a. Centralized and integrated services
2. Person First Policies and Treatment
3. Universal Instructional Design for maximum opportunities to participate
4. Disability Representation at decision level (appointed, advisory, et al.)
5. Wholistic and Wellness based services (i.e. include more than medical and sport)
6. Universally Designed Environments – (i.e. colour, directions, physical access etc.)
7. Individual and collective awareness (i.e. My disability and everyone else's is important)
8. Strength based problem solving
9. Come prepared and focused – (i.e. be prepared to address the topic of the meeting and/or consultation)
10. Alternatives / suggestions must accompany complaints
11. Empathy sessions – Sensitivity Awareness

Once we are there, show us you are happy we made it!!!

After:

1. Ongoing contribution to discussion (i.e. multi-media/multi-sensory approaches)
2. Resource awareness using multi-media / multi-sensory
3. Follow-up on implementation and decisions

Keep us involved and invite us back.