

Occupational Therapy Now

is published six times a year,
(bimonthly beginning with
January) by the Canadian
Association of Occupational
Therapists (CAOT).

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Yes I can!



Contents

VOLUME SEVEN • ISSUE FIVE • SEPTEMBER/OCTOBER • 2005

3 Greetings from the CAOT President

Diane Méthot welcomes you to the Yes I Can issue of *OT Now*.

5 Occupational therapists: Champions of disability supports

Randy Dickinson, a CAOT board director, reminds us that although we have an obligation to provide sound advice to a client, the final decisions rest with the individual.

7 Recognizing socio-economic rights is key to inclusion

Inclusiveness depends largely on society's predominant values. Lyn Jongbloed explains the connections between values, political agendas and socio-economic policies.

9 Inclusiveness through community development

Gayle Restall, Leanne Leclair and Sheila Banks take a look at the meaning of community building and the roles occupational therapists may play in promoting inclusiveness.

12 Our contributors

Read about the many authors who volunteered their time to write for this issue of *OT Now*.

13 The Comfortable Kitchen

Designed to help people with mental illness improve their cooking skills, Patricia Downing says the real benefit is cooking and eating with other people.

15 Inclusiveness through mobility aids

Many care facilities require residents to be independent and mobile. Joanna Rainer describes how a power wheelchair raised one resident's spirits, got him out of bed and gave him two new occupations.

CANADA POST AGREEMENT #40034418

ISSN: 1481-5532

Occupational Therapy Now is indexed by CINAHL, OTBIBSYS and OTDBASE.

16 Aging with a disability: Strategies for enabling occupational transitions

James Hunsberger with occupational therapy researchers Lynn Shaw, Ann Schweitzer and Sarah Burns share strategies that might optimize or facilitate participation in meaningful occupations as one ages with a disability.

19 The Canadian Holocaust – Retrieving our souls

An inflammatory label but the harsh truth. Rachel Andrew helps non-First Nation health professionals and others to understand the effects of Residential School Syndrome and how to build trust and rapport with First Nation clients.

21 Public information and communication technologies: Improving access or creating new barriers?

Money machines are great — if you can reach them! Jacquie Ripat, James Watzke and Gary Birch have developed a system to test the new convenience machines for accessibility.

23 Overcoming barriers: Becoming an occupational therapist when you cannot see

Paulette Guitard was the director of the occupational therapy program at the University of Ottawa when Sylvie Lirette began as student. Together they learned what it takes to create an inclusive program.

25 Practising what we preach

Lessons learned from the University of Ottawa experience.

26 Reflections on a student research project: Experiences of university students with physical disabilities

Susan Guenther boldly asked: “Did your research team include persons with disabilities?” Met with silence, she later went on to become an active researcher herself. Read about her journey.

31 Implications of universal design principles to vehicle design

Jan Miller Polgar, Lynn Shaw and Brenda Vrkljan are helping car manufacturers to design cars that fit more than the average 25-year-old male.

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Greetings from the CAOT President

Diane Méthot

On behalf of the CAOT Board of Directors, staff and members, I welcome you to this special issue of *OT Now* which we have titled “Yes I can!” The “I” in this message is not the occupational therapist but the individual person. It’s also the theme that we have chosen for our National OT Month this coming October. We hope it will spur discussion regarding the many ways in which we, as occupational therapists, can advocate for a more inclusive society. While occupational therapists help individuals to participate in the activities and occupations that are important to them, they have also realized that the barriers people face can only be overcome by looking at the environment in which the people live, work and play.

In late June, I had the pleasure of attending the annual conference of the British Association of Occupational Therapists. One of the speakers was Sue Maynard Campbell, a solicitor and manager for Equal Ability Limited which is a company that assists organizations to remove barriers to inclusion, particularly for disabled people seeking employment and services. In her keynote address, she categorized barriers with 5 Ps: physical, policy, practice, people and power. I thought it was a great way to capture the barriers that must be addressed so people of all abilities can confidently say “Yes I Can,” regarding the occupations that are most meaningful to them.

Physical barriers are often what first come to mind regarding inclusion, and occupational therapists address many of these with their clients. For some occupational therapy students, one of their first assignments is to spend a day in a wheelchair. I recall my experience and how frustrated I was trying to do my groceries. Every time I needed an item I was unable to reach it from the shelves, an activity far too many people take for granted.

Policy can influence our society, our communities and our workplaces. CAOT works diligently with the federal government and many national consumer organizations to promote the importance of occupation to the health and well-

being of the people of Canada, and a major message is one of “inclusion”. How many times have occupational therapists come across policy that actually discourages people with disabilities to return to work or to return to their home? We hope that our present work in two large primary health care initiatives will help people to access the services they need, when they need them and before they are excluded unnecessarily from many aspects of our society.

What about our own practices? How inclusive are they? Do our admission criteria prevent direct referrals to our services? Are we available to those who are willing to pay privately for our services? Do extended health care and other insurance plans break down barriers or build new ones? At what time and at what place can people access our services? The profession has made a dramatic shift to community base care. Some hospitals have initiated 24–7 and emergency care services. There is more to be done.

I am very proud to be part of a profession whose core purpose is to increase people’s participation in their occupations of choice.

Unfortunately people can be barriers too. Last year in our special issue we looked at the ways in which we could encourage our workplaces to be inclusive and supportive of people with mental illness. We, along with the Canadian Alliance on Mental Illness and Mental Health, identified stigma as the number one barrier. Have we made any progress this past year? Are there more workplaces that understand how to respectfully accommodate people with mental health problems?

Power balances also require careful attention. Our role, as a professional with expert knowledge, can put us in a position of power, but this must not be abused. We need to frequently



Greetings continued from page 3

ask ourselves: do my actions, my attitude and even the words I choose, empower clients or intimidate them? Sue in her keynote said that she suspected that many occupational therapists don't feel powerful at all but when some clients look at the therapist, they are intimidated. She explained that they do not find it easy to say "no," or to question "why," and she suggests that to be true allies, we must give up some of our power.

Client-driven (or person-driven) care is a term introduced in the mid-1990s that is now being used more in service delivery. In this model the person is not in the centre, with caregivers and service providers scurrying around them, but

in the lead and directing the services they need. On page 5 our Board Director Randy Dickinson describes the subtle but important shift that we, as occupational therapists, must make to ensure that the decisions lie with the person and not ourselves.

Our mission, values, education, and code of ethics reflect our dedication and help to guide our actions both with individual clients and in our advocacy activities. We hope the articles in this issue will provoke many discussions and lead to changes that will help more people to confidently assert: "Yes I can."

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Occupational therapists: Champions of disability supports

Randy Dickinson

I recently watched a recruitment ad for the armed forces that used the slogan: *Be All That You Can Be!* I was reminded of the similar objective of effective occupational therapy which is to enable persons to get on with living their independent lives by helping them become all that they want to be. Unlike the army, however, an occupational therapist cannot order a client to do exactly what the therapist believes would be in the person's own best interests.

Canadian occupational therapists are committed to a person-centred approach through their interventions, but may in the end become frustrated by clients who do not immediately accept and act upon good professional advice.

All rehabilitation professionals need to understand that they have an obligation to provide sound advice and current information to their clients about the options that are available to them, but that the final decisions still rest with the individual who will live with the consequences of those decisions. Speaking as both a person with a disability and a consumer advocate, I can certainly appreciate the value of working in partnership with my rehabilitation professionals. They can offer me tremendous insight based on their training and experience in dealing with similar situations. I am, however, in the best position to know what is important to me and what I am prepared to do in order to achieve my personal goals. I need to maintain control over my life, as is the general wish of most other citizens. Clients should not be expected to blindly accept all the external choices presented to them just because the suggestions come from a well-intentioned professional. Consumers in other areas feel the same way about their relationships with the rehabilitation professionals involved in their lives.

In my experience, there may be differences in how someone will respond to suggestions about his/her needs for disability supports; it can depend on whether that person was born with a disability (or has dealt with their functional limitations for a long period of time) or has more recently developed a new level of disability through illness, an injury, or the next phase of a progressive disability. Some consumers have

grown accustomed to professionals making the decisions about what will be appropriate to meet their needs, while others will question such recommendations and either ignore them completely or be very resistant to such input. Many consumers will have difficulty in accepting new functional limitations that will impact the quality and degree of independence in their daily lives. To accept the necessity to use assistive technology and/or personal care supports can be a huge blow to a person's ego and fragile sense of self-esteem, even if there are huge potential benefits to one's quality of life by using such options.

To be effective, occupational therapists have to invest the necessary time to establish a positive trust relationship with the client and learn as much as possible about the real environment where the client carries out the activities of daily living in the home, school, workplace and community at large. They need to listen carefully and understand what that person's priorities are and how they may be achieved within the framework of the personal and financial resources available to that person, even if some of the priorities differ from those of the professional. Only in this way can the therapist enable clients to honestly and fully communicate their needs and how their lives might be improved by the use of specific disability supports. The therapist must have that honest and complete information in order to offer the best and most useful advice.

Individuals may require time to adjust to changes in the way that they will carry out their activities of daily living and to get over any feelings of self-denial or embarrassment in their use of new disability supports. It may be helpful to link consumers with others with similar issues who have successfully incorporated such technical aids and/or personal care assistance, to the point where the aids become merely tools

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Disability support programs tend to lag behind advances in technology and pharmaceutical products.

helping them to satisfactorily participate in the activities of their choice. It would also be useful for consumers to have the opportunity to try out different technical aids and different models of mobility devices, so that they can experience how effective such a device will be in meeting their own particular requirements. Most people would not be happy with having to buy a new car just by looking at a picture provided by the salesperson. Most will want to take the different models for a test drive and see how the vehicle feels before they make a final decision that incorporates their needs and ability to pay. I will confess, for example, that I resisted for a long time the options of using a cane, a reach extender, a sock puller and especially a scooter until I had the chance to try them out on my own and to discover how helpful they were to me and how much control they gave me back in my life.

For the purposes of this discussion, we are using the definition found in the report from the Federal, Provincial and Territorial Ministers for Social Services *In Unison 2000: Persons with Disabilities in Canada* which states that "Disability supports are goods and services that assist people with disabilities in overcoming barriers to participating fully in daily living, including economic and social activities."

After the therapist and the client have agreed on what disability supports are necessary to achieve the particular goals for that particular individual, we have to ensure that the clients will have access to the necessary resources to actually acquire the disability supports in a timely manner. This can be a dilemma. Occupational therapists can be a valuable resource in identifying various funding sources and equipment and service providers that could apply to their clients' situations. Clients' ages, where they live, what type of disability, how the disability was caused, household income level, whether clients are working and have health insurance coverage, and what particular disability supports are required, are all factors.

I think many people would be surprised to discover that too many Canadians with disabilities are not able to acquire needed disability supports in a timely and comprehensive manner. The public assumes that if a person requires a wheelchair, or an assistive communications device, or a personal care attendant, that there are adequate public and community programs available to meet such requests. Many citizens, however, do not have private health insurance and may have

just enough income to prevent them from qualifying for even the limited public assistance programs. Many citizens do not have adequate finances to cover the extra costs of their disability supports. Most charitable organizations are stretched beyond their limits and are unable to keep up with individual demands for even basic disability rehabilitation items. A number of disability support programs are linked to eligibility requirements around employment-related services. This automatically excludes many persons who are not presently able to be in the workforce and/or those who have left the workforce due to reaching retirement age. Disability support programs tend to lag behind advances in technology and pharmaceutical products that may be new or expensive but which are also highly effective in improving independence and the functional abilities of the user. These newer items may not be considered as eligible expenses under the various public or private programs. Current income tax provisions do not come close to covering actual out-of-pocket costs for most disability-related supports. Remember that income tax deductions do not benefit low income consumers who pay no income tax.

Occupational therapists could greatly assist consumers who require disability supports by systematically advocating on their behalf to governments at all levels, to the media, and to the insurance industry to improve the present range of options and levels of coverage of citizens unable to personally pay for all of their disability supports. Such a campaign could be done in partnership with other rehabilitation professional associations along with consumer and disability based groups who are already interested in this huge inequity. The lack of access to the very supports necessary for such persons with chronic disabilities prevents them from enjoying all the rights and responsibilities of full citizenship and from participation in all of the opportunities available in their communities. It also frustrates many therapists who are not able to see their clients reach their full potential.

I would like to close with the words of former First Lady Rosalyn Carter who said, "A leader takes people where they want to go. A great leader takes people where they don't necessarily want to go but ought to be." Anything that the profession of occupational therapy can do to improve consumer access to required personal disability supports would truly be an act of great leadership.



Recognizing socio-economic rights is key to inclusion

Lyn Jongbloed

Advancing the Inclusion of People with Disabilities¹, published in 2004, is the federal government's most recent comprehensive report on disability in Canada. It is intended to increase understanding about the meaning of inclusion and how progress toward inclusion can be measured. The government engaged 23 national disability organizations in the process of identifying aspects of inclusion. The six aspects identified were disability supports, skills development and learning, employment, income, capacity of the disability community, health and well-being.

For each aspect of inclusion there are indicators of progress. For example, one indicator of disability supports is the percentage of adults who have the assistive aids they need for everyday activities.

Advancing the Inclusion of People with Disabilities concludes that while there has been limited progress in the area of employment (e.g. the employment rate for people with disabilities increased between 1999 and 2002), there has been no progress in the other areas of inclusion. This article briefly examines reasons for this slow progress. The extent to which social policies assist people with disabilities to become fully included in society depends to a large extent on predominant values. 1980 was the International Year of Disabled Persons and in the 1980s there was considerable public support for policies which increased the inclusion of people with disabilities; and there was progress in areas such as access to public buildings and transportation. The lack of progress in any areas of inclusion over the last 15 years can be traced to structural and ideological changes in the political and economic realms in the early-to-mid- 1990s. These changes were prompted by shifts in the political agenda that valued deficit reduction, economic growth and corporatism. This was used to justify major cuts to social assistance, employment insurance, disability pensions, disability supports and community-based programs (including disability organizations), all of which are important to the inclusion of people with disabilities. These cuts reflected an ideological shift from the belief in the rights of citizens to receive government and social supports to the belief that individuals are responsible for provid-

ing for themselves, and that macro-economic needs are more important than social needs².

How effective have human rights provisions been in enhancing inclusion? The 1982 Canadian Charter of Rights and Freedoms created the possibility of articulating the rights-based component of public policy decisions. Section 7 of the Charter guarantees "the right to life, liberty and security of the person" which is related to the UN Declaration's "freedom from want". However, 22 years of Charter litigation reveal that both litigants and the courts are reluctant to deal directly with the "claims emerging from the right to be free from want."³ Civil and political rights have been championed by Canadian courts when the federal government uses repressive criminal legal power, but there is considerable hesitation regarding social, economic and cultural rights and

Clients/consumers have taught occupational therapists that exclusion impacts all of us.

protecting weaker parts of the population on grounds other than discrimination⁴. Thus in the area of employment and people with disabilities, for example, governments have focused on anti-discrimination legislation and individual rights. An individual who has been denied workplace accommodation can therefore file a complaint under the Human Rights Act. However, people with disabilities have to deal with inadequate income support, lack of opportunities and little political influence, which stem from unfair distribution of resources, not from discrimination⁵.

Clients/consumers have taught occupational therapists that exclusion impacts all of us. The values and services of

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occupational therapists strongly support the inclusion of people with disabilities. Therapists value inclusion; their services enable participation and inclusion of people with disabilities in roles that are important to them. They are actively involved in four aspects of inclusion named in *Advancing Inclusion of People with Disabilities*: Disability supports, skill development, employment, and health and well-being; but more is needed.

In the 1980s, the disability movement framed disability as a minority group issue, i.e. disability is something that will be experienced by some, but not all, people. However, there is a growing recognition that disability is a universal human condition that we all share to some degree. This is evident in the *International Classification of Functioning, Disability and Health* and in *Advancing Inclusion of People with Disabilities*. Perhaps this will encourage efforts at political and economic levels to increase efforts aimed at inclusion.

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Inclusiveness through community development

Gayle Restall, Leanne Leclair and Sheila Banks

Have you ever asked yourself what would need to happen to build an inclusive community? Have you ever thought about how to enable people of varying abilities to participate in the community activities you enjoy, or whether new programs need to be developed to replace unhealthy activities? Have you ever considered how to make the best use of the strengths and resources of your community?

Occupational therapists often ask these types of questions. These questions ask about how to build strong, vibrant and healthy communities. The process of building communities is often called community development. Occupational therapists believe that community development is an important way to promote community participation by people of diverse abilities, cultures and interests.

Before beginning the community development process, it is important to define community. Defining community is important because it influences the identification of characteristics, issues, values and resources that play a central role in the community development process. There is no consensus in the literature about how to define community and which definition should be used when discussing community development. In general, a community can be defined as a group of people who share either common interests or circumstances, or share a geographic location such as a neighbourhood¹. This means that individuals may belong to several different communities. The meaning and significance of each of the communities may vary enormously for any individual.

Once a community is identified, the next step is to

define what is meant by community development. The literature on community development is also strewn with many definitions, because there are different social and intellectual traditions that have contributed to community development work. As a result, communities emphasize one aspect of development over another, and respond to the different social, cultural, political and environmental contexts in which community development has been applied internationally. There appears to be some consensus forming around what community development means in the Canadian context. Labonte² proposed that community development is "...the process of organizing and/or supporting community groups in their identification of important concerns and issues, and in their ability to plan and implement strategies to mitigate their concerns and resolve their issues."

Several generally agreed-upon principles are used to guide community development. Community development is committed to equality by breaking down hierarchies and power relationships³. It values the knowledge, capacities, skills and experiences of community members, addresses the priorities identified by and common to those communities, and empowers members to participate more fully in community decisions⁴. It allows communities to take ownership to improve their health through enhancement of their leadership capacities, and promotes the development of client-centred health and social services⁵. Inherent in the process of community development is change: change in social, economic, cultural, political, and physical environmental situations for the betterment of the community⁶. People with disabilities are able to participate more fully in communities through equalization of opportunities and the concept of social inclusion for all⁷.

Occupational therapy and community development

Occupational therapy has much to contribute to community development. It is concerned with the occupations of everyday life which can include everything from paid employment



Engagement in meaningful occupations contributes to the economic and social capital of communities⁸.

to the things that people do to look after themselves and to enjoy their leisure time. Engagement in meaningful occupations contributes to the economic and social capital of communities⁸; however not all people are afforded the same opportunities to participate in meaningful occupations, resulting in occupational injustices. “Justice is an implicit social vision in occupational therapy... a justice of inclusion in ordinary, daily life...”⁹

The focus of occupational therapy is on the interaction between people, their occupations and the environments in which they live, work and play. This interaction results in what occupational therapists call occupational performance¹⁰. Occupational therapists recognize that health and disability influence occupational performance and that occupational performance influences health. Successful occupational performance is a primary focus of occupational therapy.

Occupational therapists have developed a strong tradition of using client-centred approaches in their work. In contrast to the traditional professionally dominated models of health care delivery, in occupational therapy client-centred practice means that therapists engage in partnerships¹¹ and view clients as leaders in the process¹². Occupational therapy processes encourage clients to identify their strengths and resources and identify the issues that they would like to address¹³. This approach is congruent with community development: community members assume leadership in identifying and implementing actions that promote the building of their communities. Professionals act as resources for communities to achieve each community’s goals and aspirations.

As a resource for communities, occupational therapists bring their client-centred approaches, knowledge of health and disability, ability to identify strengths and resources, and a focus on occupations, to participate in a variety of roles in community development. All of these roles assume that the community takes the leadership role in guiding the process. Occupational therapists support community development by using their knowledge and skills to promote occupational performance within communities. Roles focus on the three cornerstones of occupational therapy practice: *people, occupations* and *environments*.

People — Creating opportunities to develop personal knowledge and skills

Occupational therapists provide mentorship, coaching, facilita-

tion and support to enable the development of knowledge and skills in community members. Members may develop basic life skills or they may choose to acquire the skills to obtain and maintain leadership roles within their communities.

Role Example

Occupational therapists work with non-governmental organizations such as family resource centres to meet the needs of geographic neighbourhoods. Using community development approaches, occupational therapists work with women in a neighbourhood to identify the daily living skills they require. The women advocate for needed resources to assist them to develop skills. Through the process of identifying needs and advocating for needed resources, the women participating in the community development process develop leadership knowledge and skills.

Occupations — Developing new occupations

Occupational therapists partner with communities to discover and develop new occupations that better meet the goals, aspirations and needs of the community. New occupations promote economic opportunities and healthier lifestyles and assist in the prevention of sickness and disability.

Role Example

An occupational therapist works with a community coalition to engage youth who are facing many social and emotional barriers to traditional healthy youth occupations such as organized sports and recreation programs. The occupational therapist partners with youth, community leaders and interested residents to support the identification of new occupations in which the youth may want to participate. A youth art studio is developed in a space donated by a local business. Youth become involved in creating art work which they display and sell. Through this process, the youth become engaged with positive occupations to replace unhealthy and high risk behaviours.

Environments — Building more accessible environments

The physical inaccessibility of community environments can be a major barrier to the participation of people with disabilities in community life. Occupational therapists apply universal design principles to create physical environments that

Community development is a viable and effective strategy for the prevention and management of disability.

allow people with varying abilities to participate in community programs.

Role Example

Occupational therapy fieldwork placements, in which student occupational therapists receive coaching from a community contact and a qualified occupational therapist, provide a resource to promote inclusiveness through application of universal design principles in municipal recreation facilities. Students work with people with disabilities and the facility staff to assess individual participation in specific recreation programs. They then recommend structural and program modifications that will allow greater participation.

Occupational therapists use their understanding of social, economic and political barriers to join with people who are marginalized in society to advocate for greater access to supports and resources. They share their knowledge and skills to advocate for the removal of social policy barriers that prevent full participation in community life.

Role Example

An occupational therapist works with a community disability group to develop skills and capacity to do participatory action research. The group develops research-related knowledge and skills, and forms partnerships with professional researchers. The group members use their experiences as persons with disabilities to inform the development, implementation and interpretation of the research. The goal of the group is to affect social policy changes that will improve the lives of persons with disabilities.

Community development is a viable and effective strategy for the prevention and management of disability; for the provision of accessible services for persons with disabilities and their families; for improving the health and quality of life of Canadians with varying abilities, in all social and economic circumstances. Occupational therapists, with their focus on occupational performance through the interaction of people, occupations and environments, provide a unique perspective in the community development process. In partnership with individuals, groups and communities, occupational therapists promote full participation in those communities.

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The Comfortable Kitchen

Patricia Downing

On January 3, 2004 there was a bitter wind that brought the temperature down to -39C. Should I cancel the cooking session of the Comfortable Kitchen? I called one person to offer them a ride, another came by bus, two walked, one of them for 20 minutes. "We're Albertans!" was the response to my surprise. With the assistance of a friend of mine (he had asked what was a Collective Kitchen and so got roped in) we cooked three take-home meals. Then we made a big lunch. We had quite a party as four of the Sisters came and we invited two maintenance men who had been working outside to join us. A memorable session!

The Comfortable Kitchen was started in 1995 by two occupational therapists working in Community Mental Health. We wanted to enable people with mental illness and who are living in poverty to improve their nutritional knowledge and cooking skills and decrease their use of fast and processed food, thereby getting better value for their food budget. While these objectives were met and appreciated, we are told that the real benefit is cooking and eating with other people.

People come to the monthly kitchen with smiles on their faces and ready to jump in and work. Depending on ability and interest, small groups are formed to make the three take-home meals and lunch. The kitchen becomes a bustling area of chopping, frying, boiling, stirring and, of course, dish-washing. There is much chatter and a distinct feeling of friendliness as people ask about each other, tell stories, and offer understanding and support if someone needs it. There is laughter and learning as people work together to figure out new recipes, discuss the use of cheaper ingredients, learn the tricks of making a smooth cream sauce and how little food



needs to be wasted. It was marvelous to hear one couple describe all of this as "a good break from work."

A psychiatric nurse and another occupational therapist have joined the volunteer organizing team and we take it in turns to

organize and run the cooking sessions. Occupational therapy students have benefited from helping. "I left that morning with a feeling of actually making a difference and feeling as though occupational therapy has an important role in providing opportunity for people to find meaning and value in their actions. This experience illustrated to me what an occupational therapist can do in the community and how important programs such as this can be," explained Maureen Stigant during a student placement in June, 2003. Task analysis and the ability to adapt are important as we have to manage both mental and physical disability. One man used bilateral upper limb prostheses, a lady had severe hearing impairment, another required a gluten-free diet. Assistance with planning, judgment, concentration, etc. are required all the time.

We advertise in community and agency newsletters, and therapists encourage some clients to come to the kitchen. The group is always changing, and old-timers welcome newcomers readily. We have men and women (mainly single), seniors and children. One man came regularly for nearly two years. He then announced that because he had turned 65 he was now going to the local senior's society for meals. We feel that his self and social confidence had improved to the extent that he knew he would be a successful member of the "normal" community, through his involvement with the kitchen. A lady and her 15-year-old son both had schizophrenia. He lived in a group home and she used the Comfortable Kitchen as a place for them to maintain contact with each other and

The group is always changing and old-timers welcome newcomers readily.



because she didn't want her son just watching TV on Saturday. We saw his productive and social skills improving and their relationship developing. Once, when I called her at home to remind her of the cooking date, she proudly said "Guess what? My son's here and we're baking cookies!" Another

memorable moment! They now live together.

Helping people improve many aspects of their lives through a productive and enjoyable activity – you can't get more OT than that! We are indebted to our sponsors, the Franciscan Sisters of the Atonement and Riverbend United Church, for making the Comfortable Collective Kitchen possible.

Inclusiveness through mobility aids

Joanna Rainer



When we talk about providing resources and supports to people with disabilities let us not forget the geriatric client.

Disability should not be considered a “normal” consequence of aging. People in their 80s and 90s can still desire and strive for their independence. And what represents independence more than being able to get from one place to another by yourself? At many assisted living and private care facilities this is the bottom line: if you cannot get to the dining room yourself, you cannot live here. This article is a case study of how maximizing independence in mobility significantly improved the quality of life for a geriatric client.

John* came to our Short Stay Unit in September 2004. He had a number of serious health problems including chronic obstructive pulmonary disease (COPD), subluxation of his left ankle and chronic edema and pain in his left knee. He was the primary caregiver for his wife until she died. They did not have any children. When his own health started to fail, he went to live with a distant relative. The goal of admission was to increase his strength enough so he could function in the relative’s home. He could ambulate for 10 feet with a four-wheeled walker and then the pain in his left ankle and knee became unbearable. When he tried to propel himself in a manual wheelchair he became short of breath after a few strokes. He spent most of the day in bed with the covers over his head. He rarely interacted with the other patients and only interacted with staff if they initiated contact.

As his discharge date drew near his relative confirmed she could not take him back into her home. His family decided Uncle John must move into a private supported living facility. The only apartment available was a 50- foot walk

from the dining room. The Short Stay Unit physiotherapist and occupational therapist knew John could not walk that distance three times a day. We discussed the option of power mobility and presented the idea to John. To our surprise, he was willing to try it. He was in the fortunate position of qualifying for medical equipment benefits from the Department of Veterans’ Affairs and the process of trialling and obtaining a power wheelchair for him was put in motion.

What did power mobility do for John? I believe it changed his life. He is able to independently get to the dining room, around the facility and outside for fresh air. He no longer has to endure shortness of breath and pain in his right leg just to get to meals. He is a permanent fixture in the lobby of the building, keeping an eye on people’s comings and goings, joking with the staff and socializing with other residents. He participates in the many social activities offered at the facility. And he has a job. Before every meal, you can see him sitting in the lobby chatting with his friend Harry*, a blind gentleman. When it is their turn in the dining room, Harry stands up and holds on to the back of John’s wheelchair. John drives very slowly and carefully into the dining room, leading Harry directly to his seat. When the meal is over, John is there to escort Harry back to his room.

A power wheelchair has allowed John independent mobility. He has the autonomy to go where he wants, when he wants, without pain or the discomfort and panic of fighting for breath in the process. He has found new joy and purpose in life. It has been wonderful to see him blossom into the funny, caring man that was hidden under that pain, depression and grief. Whenever I pass through the lobby and see John sitting there, petting the resident cat, teasing the receptionist or helping Harry to his seat, I think “Yes. This is what it’s all about.” Maximizing independence. Facilitating autonomy. Finding meaningful occupation in life, at any age.

*not his real name

Aging with a disability: Strategies for enabling occupational transitions

James Hunsberger, Lynn Shaw, Ann Schweitzer and Sarah Burns



photo credit: Paul Fischer

Aging with a disability means learning how to accept deeper water, and deeper water does not mean drowning. In my life, interdependency and self-sufficiency kept me close to shore where my feet remained grounded on the bottom. Interdependence and resourcefulness now allows me to grow and to move out into deeper water, letting go, going with the flow, being buoyed up, defying gravity, swimming, moving on, and growing up. — James Hunsberger

In Canadian society persons with congenital disabilities are living longer. Interestingly enough this group of individuals report experiencing new challenges as they transition into older adulthood. Beyond the growing access to literature on assistive devices, there is limited information available which can best prepare persons for achieving occupational fulfillment in this stage of life. Few studies exist exploring multi-dimensional issues relating to aging with disability, and little information exists to direct health care providers in how to work in partnership with persons aging with disabilities or to assist them in discovering meaningful occupational choices and enabling optimal participation.

This article elaborates on a partnering process with a therapist-researcher which enabled James to build the confidence required to move into deeper waters.

The Journey

The daily occupational struggle with aging and disability, combined with his retirement, provided the impetus for a self-reflective narrative by James aging with cerebral palsy. The quest for greater insight into aging with a disability and how to be successfully engaged in meaningful occupations in retirement led James to welcome a therapist-researcher to assist him with unravelling some of the complexities of his life's journey. Together over three years they used van Manen's approach and recorded, documented, analyzed and reflected upon his narrative¹. Stories were shared from childhood, teenage years, young adulthood, adulthood and older adulthood. An occupational perspective of "being, doing and becoming," as described by Wilcock², was used to gain a deeper appreciation for various occupations, their meaning, and the complex array of personal and societal barriers affecting these occupations throughout James' life. Personal insights gained through this process of reframing life, disability and aging, and occupation experiences, increased James' understanding of his previous need for independence. He also began to welcome a transformation that would embrace a lifestyle filled with interdependence and resourcefulness. He elaborated:

When I reflect on the disability container I see that part which by and large forced me to react and to rally around the challenge of an occupation or a job, a time which called forth a spirit of independence, self-determination and self-

photo credit: Christopher Allen



sufficiency. When I reflect on the aging container I make progress towards proactively deconstructing the impact of my disability. For this to happen required time and may have caused me to take a longer time to 'grow up', which in itself is a mixed blessing. The aging process was required to unravel and reveal my disability; to recognize my shortcomings and assets; and to acquire a passion for interdependency and resourcefulness.

Enabling occupational transitions: Insights gained and shared

Insights from this shared journey and self-discovery revealed strategies that may be considered useful by consumers, caregivers and occupational therapists in assisting persons who are aging with disabilities to achieve their occupational potential and fulfillment. The following strategies are not focused on enabling independence per se; rather they afford persons aging with disabilities an insider's perspective on action strategies that might optimize or facilitate participation in meaningful occupations as they age.

Committing time and energy to ensure a healthy mind and body through forming a healthy identity

Today, my identity is found in seeing myself as 'a be-comer,' a person who has taken time to integrate the 'being' part of my life with the 'doing' part of my life. At times this proves difficult in today's society, which places so much emphasis on who we are by what we do. But to me, connecting the being, the doing and the becoming parts of life is very important. This integration is also a part of a transition from a wilful spirituality to a spirituality of willingness. So, in the aging process, I have met this challenge, and I see myself as a person who has tried to integrate and balance the 'uneasiness of self-identity' with the 'joy of self-confidence.'

Recognizing and accepting a becoming approach to life, attaining balance between the being and doing aspects of life through pacing oneself

Aging and the challenges of disability are more successfully met by being in tune with my body. I am learning how to be gentle with myself, to note the pain, set priorities in light of my energy, to say no at times, and to schedule rest breaks. I do this by planning a time to be; a time to do; a time to become; a time to go to the 'Y'; a time to walk; a time to relax; a time to scoot; and, a time to celebrate.

Accepting a pro-active approach to manage depression, fatigue, isolation, anxiety and loneliness that can occur with aging through using animal-assisted services

Lady Cléo (my special skills dog) empowers my left side where I have the most spastic and athetoid movement. Today, Lady Cléo steadies me while walking and keeps my good side open for balance. Lady Cléo helps me to embrace the impact of cerebral palsy on the aging process, and to challenge fatigue, isolation, loneliness, anxiety, and depression. For instance, Lady Cléo never lets me sleep in. She is the first to remind me in the morning of the importance for schedule and routine. She keeps me from obsessing with my work and reminds me of the important things like pee time, treat time, gym time, walk time etc.

continued on page 18



photo credit: Christopher Allen



Maintaining the spirit of feistiness to face the challenge of aging and the uncertainty of not knowing disabilities still yet to come through sharing stories and learning to self-disclose

It is a human condition to be somewhat guarded about our weaknesses, especially when we are young, and even more so when we feel the shame or shortcomings of a disability. My story reveals how difficult it was to disclose my disability in my younger years. Learning how to disclose is especially helpful to appreciate and to understand life's paradoxes and contradictions, which become more meaningful as one grows older.

I always enjoyed telling stories, but listening to stories and being able to tell my story becomes more meaningful the older I become. What a wonderful way to learn to more fully self-disclose! Today, I see telling stories and self-disclosing as a means to keep my health vibrant; be present for peer support; and learn to be affirming and encouraging toward others.

Embracing and achieving occupational potential through learning to be resourceful and interdependent

This is a process itself and involves learning how to ask for help responsibly. I need time to own what I am trying to do, and I need time to assess what help is required. When I understand 'the what and the why' of my need for help, it becomes much easier for me to ask for help. Once I know



photo credit: Paul Fischer

what I am asking for, and I feel responsible for why I am asking them, I am truly authentic in asking for help. However, as I grow older, it is making more and more sense, and I am feeling more and more comfortable to ask for help in order to conserve energy; avoid anxiety; and to better pace myself throughout the day. It is life's intensity that challenges the limits of my resourcefulness and interdependency.

Enabling occupational transitions: The partnering process

The partnering process used to enable James to explore and to discover new understandings about aging with a disability was achieved through both Lynn and James adopting an openness to reciprocity, establishing a shared commitment, exchanging discoveries, knowledge and resources, and engaging in a reflective process through an occupational perspective. These endeavours characterize the collaboration between a senior activist and a therapist-researcher and may be useful to others in the development of other partnerships. For Lynn, as a therapist, this type of work with consumer advocates and consumers themselves requires a willingness to enter into a partnership with an openness to learn and to grow, as well as a readiness to make a conscious commitment to information exchange and the benefits of reciprocity. In addition, therapists need to recognize the important and inherent value in offering an occupational perspective to assist others like James in finding a self-discovery process and an avenue for achieving improved health and well being.

The Journey continues...

At this stage of the journey, revelations unveiled that living with disability is a presupposition to aging and embraced interdependence is essential for realizing occupational potential and fulfillment. Hopefully, there is more to come and this collaboration is only a beginning, as this partnership grows beyond itself and builds upon the life narratives of others aging with and into disability.

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photo credit: Paul Fischer

The Canadian Holocaust – Retrieving our souls

Rachel Andrew



THOMAS MOORE, AS HE APPEARED WHEN ADMITTED TO THE REGINA INDIAN INDUSTRIAL SCHOOL.



THOMAS MOORE, AFTER TUITION AT THE REGINA INDIAN INDUSTRIAL SCHOOL.

Library and Archives Canada/Credit: Tompkins Studio/William James Tompkins collection
Accession 1936-270, DAPCAP 398274

I was recently asked to speak at the CAOT Conference in Vancouver about building rapport with First Nations clients and how to understand their view of special needs children. I am a First Nations woman, the mother of three challenged children, and the Health Director of the Mt. Currie Health Centre. These professionals seem to be very caring and genuine in wanting to help people, all people. They need, however, some tips on how to build rapport with First Nations clients, especially the parents among them, because they get many unexpected responses and reactions for their caring and diligence within their fields of science.

My oldest son has Asperger's Syndrome, my second son is very gifted, and my three-year old daughter has Down Syndrome. I want nothing to do with pity. We are never pitiful. Actually, I consider myself special for having been chosen to have children who have been sent to earth with challenging life/spirit missions. It is an honour to have them, and I always say "I wouldn't trade them for anything."

To understand where First Nations people are coming from, you must educate yourselves in one important thing: residential schools. It isn't nice, but it's crucial to realizing how we got from a balanced, holistic, spiritual, respect-everything, wind-in-our-hair type of people to the people we are today. I always say, "We didn't wake up one day and decide to be drunks and drug addicts." It's a lot like learning about the Jewish holocaust or the history of black slavery in the U.S.

We call it many things — Residential School Experience, Trauma and Syndrome. It affects 100% of the First Nations people living in North America. However, younger generations of First Nations may not know what their parents or grandparents endured although they live with the aftermath.

It is the root of many disorders in First Nations people, including drug and alcohol abuse, suicide, teen pregnancy, sexual abuse, spousal assault, chronic diseases, low self-esteem and depression. Even in having these incredible challenges we never really lost our identity or pride as you might assume we have; we are great survivors.

I remember my mom seeing a movie on TV about residential schools and refusing to watch it even though I wanted to watch it. She said, "I'm not willing to go there, yet." Mom said, "It was enough to take small children out of their homes against their will to bring them to an unloving, cold place! That was enough to be traumatic!" I think my dad was more resistant to talk about his experience. My dad told me that he only spoke our language when he got to school and was beaten every time that he did. Imagine someone coming into your home and telling you, "Give us your children or go to jail." He was forbidden to talk to his sister who he would see in the hall or playground. I remember when my young son and niece got cute haircuts. My mom took one look at them and said, "Hmm, residential school hair cuts."

The myths are: that it was over 100 yrs ago, it wasn't so bad, or violent abusive stories are only isolated ones. Wrong. The stories you have heard are common and heartbreakingly common. I gained tremendous respect for our ability to survive, especially in my parents, and even thrive in life knowing what they have been through. I am sure there are more incidents that they do not speak of or will not speak of or even admit happened to them. Residential School Syndrome is similar to post traumatic stress syndrome defined in the DSM-IV and attempts have been made to classify the symptoms.*

continued on page 20



Share your human experiences and bridge them where possible, especially if you have had challenges with your own children.

Even though I was lucky enough to not go, and my generation was the last to go, I was affected by my parents' experiences, as they never learned how to parent from their parents. They did an awesome job raising me considering that. The last residential school for my people shut down in the mid-80s. Not too long ago, I went to a workshop where the facilitator asked, "Did your parents parent you like a nun or priest?" Wow, that was sure something to think about. You see, survivors have similar behaviours, such as hyper vigilance, black and white thinking, defence mechanisms, totally accepting or rejecting religion, and many unconscious reactions to non-First Nations people, especially if they are in positions of authority. My list could go on and on.

I strongly recommend you understand this point of view before knocking on the door of a First Nations client. Some of them may never trust you because of the colour of your skin. Dress as casually as you possibly can. Take a look at how you see First Nations people, because if you see yourself as above them they will know immediately when they meet you. Share your human experiences and bridge them where possible, especially if you have had challenges with your own children. Realize that a person who may have been beaten at school to keep a sterile-clean living area may now live in a messy home. Get over it. Always remember why you got into your profession: because you have compassion, and you want to make the world a better place. That may not always happen through the methods you learned in university. In fact, very few will. If you are fake in any way, you will be shut out.

Read as many books as you can on residential schools. A few that I would recommend include *Behind Closed Doors* by Mary Fortier, which is about a Kamloops Residential School. There is also a manual by The First Nations Healing Foundation call *Reclaiming Connections: Understanding Residential School Trauma Among First Nations People*. The web site: *Voices of the Canadian Holocaust: Native Survivors' Testimonies About Crimes Against Humanity* <<http://www.hiddenfromhistory.org/voices.htm>> may also help you to understand the extent of our trauma.

I believe the origin of the abuse cycle is a cataclysmic interference of our balanced social structure. Social problems do not stem from our traditions and culture. Traumatic ordeals are not isolated but rather quite common or typical. I am touched and honoured that you want to learn about this, thank you so much for caring.

Postscript by Alison Gerlach

I am in the very fortunate position of being able to call Rachel my friend, my client and the manager of the occupational therapy services I provide to her community on reserve land. Rachel is also my teacher. "Have you thought about the residential school system? I really think you should" was advice that Rachel gave me. It was crucial to planning a study exploring First Nations values and practices of raising a child with special needs and collaborating with non-First Nations health professionals.

As a Caucasian occupational therapist employed by a First Nations Band, I experience varying levels of mistrust in many interactions and attempts at rapport building with both First Nations colleagues and clients. Becoming curious and more informed, talking with First Nations colleagues about the residential school system has provided me with a context to better understand their world view and their behavior towards non-First Nations professionals perceived to be in positions of authority.

In addition to Rachel's recommended reading on this topic I would strongly recommend the article cited below, especially if your work involves First Nations families and children. As Rachel warned "it's not pretty" but without this knowledge we (non-First Nations professionals) risk inadvertently perpetuating colonial and stereotypical beliefs and practices and further fueling a strong historical foundation of mistrust.

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Editor's note: Watch for more information regarding Alison's experiences collaborating with an Aboriginal organization to develop a guide for culturally-focused early intervention therapy programs for Aboriginal consumers, which will appear in a future issue of *OT Now*.

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Public information and communication technologies: Improving access or creating new barriers?

Jacquie Ripat, James Watzke and Gary Birch

Public information communication technologies (PICTs) are a new way of doing business, allowing people to access information, money, and various products in a convenient and timely fashion. PICTs, including information kiosks, automated banking machines and ticket/fare dispensers, are increasing in popularity as businesses and government become familiar with the many services and benefits that PICTs can provide.

Although designed to increase the efficiency and convenience with which information is shared and transactions are completed, the development of PICTS has occurred largely without the consideration of the access requirements of people with disabilities. Lack of access to a PICT renders the information or transaction functions useless. Inaccessibility of the PICT can occur when technology features make operating or interacting with the PICT difficult, or barriers in the environment leading up to a PICT create navigational challenges. These barriers can prevent many people in society from effectively using PICTs.

Who has difficulty accessing PICTS?

The 2001 Statistics Canada Participation and Activity Limitations Survey identifies that 12.4% of Canada's population report having a disability; while for those 65 years of age or older, the prevalence is as high as 40.5%¹. However, the number for whom PICTs may not be accessible is much larger if we consider the potential difficulties faced by many others in addition to those with disabilities. Older individuals with decreased eyesight or people who are blind will have difficulty reading screen instructions in small font. Parents

pushing baby strollers and individuals using wheelchairs might not be able to reach a PICT located at the top of a few stairs. People who are short in stature and those with upper limb arthritis may have difficulty reaching or manipulating buttons or touch screens. People for whom English is a second language or individuals with learning disabilities may have difficulty following complex written instructions. These numbers represent a considerable percentage of the population for whom the technology may not be useful.

Lack of access to a PICT has consequences for many. Individual users may become frustrated and avoid using the PICT of a particular business owner. City planners may find that some individuals opt out of living in a particular neighborhood that is not accessible. Business owners may lose customers if their technology is not accessible. Government agencies who want to share some type of information may have difficulty doing so.

Occupational therapists believe that the environment can alternately constrain or facilitate the performance of desired occupations²; they are also knowledgeable in the concepts of universal design. Universal design refers to the "design of products and environments that are usable by all people, to the greatest extent possible, without the need for adaptation or special equipment."³ Occupational therapists are thus committed to ensuring that environments are inclusive of as many people as possible. Occupational therapists are key professionals to be involved in the identification of inaccessible technologies and the development of solutions to promote access.

continued on page 22



Researchers Gary Birch and Christine Flegal assess an underground parking meter machine.



How can we test for accessibility?

Use of an environmental audit to identify the main issues of inaccessibility is one concrete way of identifying the barriers related to a specific PICT. The Public Information and Communication Technology Assessment Tool (PAT) is a paper and pencil questionnaire designed for use by any individual or group who is interested in determining the accessibility of PICTs; it also provides key references on how to make PICTs more accessible. The PAT is one key deliverable under a large SSHRC¹-funded project entitled New Technologies and People with Disabilities Research Alliance (Principal Investigator – Deborah Stienstra, University of Manitoba). The PAT was developed by the authors: Jacquie Ripat, an occupational therapist, James Watzke, an environmental psychologist and Gary Birch, an expert in the technology needs and issues of people with physical disabilities. Consultation from individuals with disabilities has occurred throughout its development.

There are three parts to the PAT. Part 1 of the questionnaire examines the accessibility of the environment leading up to the PICT. Part 2 addresses the accessibility of the environment immediately surrounding the PICT (less than two metres from the PICT) and identifies barriers and facilitators that exist close to the PICT. Part 3 assesses the PICT itself and its various components such as the height of the PICT, the layout of the keys, and the presence or absence of audio output. The completed questionnaire can provide an indication of the overall accessibility of the PICT, or alternatively can provide an indication of how accessible the PICT is for individuals with a specific disability (e.g., learning disabilities, mobility impairments or visual impairments).

Who should use the PAT?

People who may benefit from the use of the PAT include individuals, business owners, disability advocacy groups, students, researchers, city planners and those involved in the PICT industry. Occupational therapists may want to use the PAT score to advocate for more accessible PICT design within a particular environment. Disability advocacy groups may wish to determine how accessible PICTs are in a defined community for one particular user group. This would allow a

¹Social Sciences and Humanities Research Council of Canada

community to develop a baseline PAT score, by which they can measure changes in PICT accessibility in their defined community of interest and compare their community with others in terms of PICT accessibility. This information could then be used to lobby for changes to improve accessibility. Business owners may complete the questionnaire to determine the overall accessibility of a PICT in the business and to identify changes that could be made to the PICT and its environment to increase accessibility for customers. The results from the administration of a PAT will provide communities, city planners and/or PICT manufacturers with ideas on how to improve the PAT score (i.e. what they need to do to make their location and PICT more accessible).

What should be done with the information?

Education and information are crucial for addressing access issues around PICTs. Users with disabilities require information on what technology exists to meet their needs and ways in which they can advocate to their communities, elected government and industry representatives. Communities require information about accessibility, universal design and the needs of all of their current and future members. Governments require information and education in order to support access through development of standards and procurement policies for accessible PICTs. Business owners require information on the needs of people with disabilities, and need to view people with disabilities as a new emerging market for their businesses. Advocacy efforts can be directed to PICT manufacturers to create more accessible PICTs. Design that considers the broadest range of physical, cognitive and affective abilities of intended users will have the effect of making it accessible to more people. The PAT is one tool that can be used to provide this needed information, to ultimately contribute to the development of more accessible and inclusive communities.

When will the PAT be available?

We are currently testing the usability and reliability of the PAT. Once complete, we will revise it and conduct another set of pilot studies with the tool. Another primary task is to finalize the “scoring” procedures of the tool, so users can have con-

continued on page 24

Overcoming barriers: Becoming an occupational therapist when you cannot see

Paulette Guitard and Sylvie Lirette

Choosing an occupation is always difficult. When you have a disability, it becomes quite a challenge.

This is the story of a young woman who dreamt of becoming an occupational therapist despite the fact that she has no residual vision. Born prematurely, she was given oxygen which destroyed her optical nerve and retina resulting in retro lenticular fibroplasia and severely limited vision. This eventually progressed to total blindness around the age of five.

After much research, Sylvie decided to become an occupational therapist to help people with various disabilities.

Before applying she met with the Centre for Special Services (CSS) and Paulette Guitard, the occupational therapy program director, to assess the resources and overall accessibility at the university. Sylvie presented a strong academic dossier and met all of the program's prerequisites. "At that meeting, I explained my functioning at school; the equipment required; the support needed from CSS and the difficulties I anticipated. Since I was leaving home and having to adjust to living on my own in an unfamiliar city, I wanted to start on a part-time basis," explained Sylvie. Fortunately, this was possible according to the policy for special need students.

Paulette remembers this meeting and realized that she needed to do some research. She recalled finding several clinicians from a variety of clinical areas who had very limited residual vision and who had followed the regular occupational therapy program. However, none of their training had included anatomy, i.e. dissection. She also consulted with the physiotherapy program at the University of Manitoba who had formerly offered a special program for the visually impaired.

Upon admission in 1996, a CSS member and the occupational therapy director met with Sylvie to determine everyone's role to ensure success. Sylvie was to voice her needs and look after her equipment such as a Braille Lite for taking notes, a scanner to convert typed material into Braille, Power



Braille for reading the computer screen, a laptop with a voice synthesizer, a regular printer for submitting papers and a Braille Blazer for printing documents in Braille. She took only half of the course load the first year, taking two years to complete the first year of the program. After that, Sylvie followed the regular program. Since she was unable to read course materials, exams and the computerized answer sheets, these had to be put into an electronic format or translated into Braille; a scribe had to be present during exams. CSS's responsibilities included Braille translation, tutors or other human resources, and funds for these

services. The occupational therapy program was to prepare course outlines, notes and exams ahead of time, provide the CSS with the list of textbooks required, and act as a resource to the CSS and other professors.

Despite this preparation, several obstacles were encountered. First, major delays in translation of materials occurred since CSS was unable to find occupational therapy textbooks available in Braille or they received the materials too late. To prevent this happening again, Sylvie ensured that course materials were sent on time according to established priorities. This entailed asking the program to have course materials ready one semester ahead of the required time. The CSS could then translate materials quickly and according to the identified priorities.

The next major obstacle came with the occupational therapy laboratories where the student was unable to see what was taking place. Sylvie served as a volunteer to have materials demonstrated to her. A classmate helped with tutoring and adapting assessment tools. The anatomy laboratories were a major hurdle as she was unable to access diagrams without specialized equipment, benefit from cadaver utilization or follow the same pace as others (high visual content). The solutions included: a private tutor and more lab time; use of tactile material or verbal descriptions for diagrams; and frequent use of the skeleton. The occupational therapy program also found a person with rehabilitation background to serve as a demonstrator.

continued on page 24



Clinical placements were also problematic. With Sylvie's permission, people at the first placement were contacted ahead to explain the situation. Although the therapists were willing to accept the student, their Department of Infection was not ready to allow a seeing-eye dog in the hospital. Sylvie remembers: "This was a time of great anxiety and stress. However, this was fought and permission to allow my seeing-eye dog in the hospital was granted [but] only two days before my placement started!"

This first placement uncovered many supports that would be needed for successful future placements. Prior to the beginning of the following placement, Sylvie contacted her supervisor to obtain the written materials to be translated. She also retained an orientation and mobility instructor (through CNIB) to help familiarize herself with the clinical setting. In addition to forwarding the required materials to Sylvie, the placement coordinator advised staff about the coming student and sought approval from Infection Control for her seeing-eye-dog. During the placement, once a week, an assistant coordinated transcription, adapted material and assessment tools, and read handwritten material that could not be scanned. The student's provincial government provided the funds to cover the assistant's salary. After the second placement, an occupational therapist was hired to adapt assessment tools and help Sylvie become familiar with the tools. As it was not always possible to have the required Braille equipment onsite, arrangements were made for Sylvie to

spend a half-day at home to complete charting.

Since October 2001, when Sylvie obtained her occupational therapy degree, she has worked in mental health. The equipment is available in her work environment, enabling her to complete charting onsite.

"I have an occupational therapy assistant available three half-days a week to observe clients' behaviours during individual assessments and during group therapy, to report the visual information I missed. She helps with administrative duties such as workload recording, photocopying and reading handwritten material, and helps adapt materials. It works out very well. I have already supervised two occupational therapy students and I enjoyed these experiences!"

This success story is due to disability supports and great cooperation from everyone. Crucial elements for success included: CSS's services, collaboration between the faculty and the CSS, support from the CNIB, financial support from the provincial government, a student's determination and positive attitude, support and understanding from faculty personnel and classmates, and the open-mindedness of the clinical milieu. Successful employment requires the same open-mindedness from hospital administrators and coworkers as well as access to an assistant for specific tasks. These crucial elements provided the supports Sylvie needed to achieve her dream of becoming an occupational therapist, thus fulfilling a meaningful occupation in its truest sense.

PICT, continued from page 22

vidence that a given PAT score (a higher or better score) does indeed mean a given PICT is more accessible. It is anticipated that the tool will be available for public use in the Fall of 2006. Future plans include development of a portable electronic version of the PAT, creation of an online database where assessments of PICT accessibility can be collected so that more information about a given community is available to interested parties, and development of an educational companion CD that provides more specific actions that individuals can take to improve PICT accessibility. Individuals who are interested in learning more about the PAT are encouraged to contact the authors at: ripatj@ms.umanitoba.ca, james_watzke@bcit.ca or garyb@neilsquire.ca.

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Practising what we preach

As rehabilitation specialists, rehabilitation science faculty advocate for the inclusion of people with disabilities; but do they practise what they preach? After our first experience, we wanted to know more about how other rehabilitation programs support students with physical disabilities, and to document our students' experiences. The results of a research project revealed that the University of Ottawa is similar to other Canadian universities. Overall, rehabilitation science programs facilitate inclusion of students with physical impairment and participants found their university experience enriching and stimulating, although not without obstacles. Academic courses presented some challenges, as did clinical placements, depending on the individual's disability and needs. From the research, we found that a positive university experience for students with physical impairments requires:

- Open-mindedness of professors and program.
- A Special Services Centre (SSC) and access to individual teaching for both labs and courses.
- Better awareness of disability issues among professors and a proactive approach to foresee the needs of students.
- Students with good self-awareness, perseverance and determination to follow their dreams.

The methodology and results of this research project were presented at the 2005 CAOT Conference in Vancouver and will be submitted for publication shortly. The students who assisted in this research include: Elise Duguay, Mélissa Lajoie, Nathalie Julie Sirois and France-Andrée Thériault. For more information, Paulette Guitard may be reached by e-mail at: paulette.guitard@uottawa.ca.



Reflections on a student research project: Experiences of university students with physical disabilities

Susan Guenther

This article contains my reflections on being a student researcher on a project that explores how students with physical disabilities navigate the university system. As a recent graduate of the University of Toronto (U of T) and a woman living with a disability, I am very familiar with this topic. My own life experience was the driving force behind this project. The study involved in-depth, phenomenological explorations of two U of T students who live with physical disabilities. Preliminary results of this pilot study were presented at the 2005 CAOT conference in Vancouver. This article, though not a research report, is a synthesis of my experiences as a university student with a physical disability and as a developing researcher, both of which have been empowering experiences in my life and career development.

Becoming a researcher

During the first year of my undergraduate degree, I became exposed to the potential disconnect between disability research and people living with disabilities. Imagine an auditorium stage with young adults with disabilities sitting on a panel listening to researchers present their findings on quality of life studies for children and adolescents with disabilities. In front of the stage, the auditorium is filled with healthcare professionals who listen intently. Being an outspoken person who lives with a disability, I found myself participating in similar panel discussions relatively often.

At this particular panel, I remember feeling quite intimidated and small. The researchers used words that I did not understand and the healthcare professionals asked questions that I could not relate to. But, as I read through the sample quality of life surveys and questionnaires, I came across a series of questions that troubled me. One survey question asked, "Do you think that your disability makes it more difficult for you to spend time with your friends?" I noticed similar questions as I read on, feeling appalled and somewhat insulted. How could anyone ask such a question of a child or an adolescent with a disability who may already suffer from

low self-esteem? Unhappy memories of adolescent emotions rushed through me. I found the courage to ask the researchers how they had developed the questions for the questionnaires. "We used a research team that included service providers with experience in the field", was the reply. "Did your research team include persons with disabilities on it?" I asked. Silence filled the auditorium.

After the completion of the panel session, many health care providers approached me and applauded me for my comment. However, I felt discouraged and disappointed at what I had learned that day, i.e., people with disabilities did not seem to have a voice in the most important places. This experience gave me a greater understanding of the importance of including individuals with disabilities on any research team that studies issues relevant to persons living with a disability.

Even though I felt strongly about persons with disabilities participating more actively in research, it did not occur to me that I could become involved in such a way. It was not until my first year of occupational therapy studies that I began to think of taking on an active researcher role. I am a curious individual and brought with me many insights into the challenges faced by students living with disabilities. With the help of my supervisor, Barry, who recognized that my life experience could strengthen both my role as an occupational therapist and as a beginning researcher, I was able to gain the courage to take on a self-directed pilot study on the experiences of university students living with physical disabilities.

Becoming a part of the research process

Much discussion between Barry and I focused on how my experiences as a student with a disability could influence the research process and how I interpreted the comments of research participants. From the beginning of the process, Barry informed me that his role would be limited to consultations on research methodology as this topic was not his area of expertise. I remember that I felt unsure of interpreting my

own life experience of going to university with a physical disability, since I often felt that I lived this experience alone. However, as Barry and I continued to discuss our roles, we came to realize that I brought with me significant expertise on the topic, and together with Barry's expertise in research methodology we were able to develop a valuable partnership.

To address my closeness to the topic area, Barry suggested that I fully examine the reflexive nature of qualitative research and introduced me to the work of Primeau¹. Primeau's work provided guidance on how to make use of my own voice in the research process, becoming a participant in the research process. According to Primeau, participating in the process and allowing my inner monologues to surface allows me to provide a richer and deeper understanding of the stories that participants share with me, through reflection and acknowledging my own important voice and reactions. I also spent a large proportion of time familiarizing myself with narrative analysis² and constant comparative method³. With one participant I used photovoice⁴ as a research method which uses photos to stimulate participant storytelling, while taped audio reflections were used by a visually impaired participant for the same purpose. Participants' everyday lives were opened to me as they described episodes with friends, family members, attendants, and teachers, and the obstacles that were encountered. All these methods allowed me to collect and pull together events in the experiences of the participants and develop a coherent story.

The remainder of this article draws from my journaled responses to the preliminary research findings and process as it unfolded. Throughout the study, I would check in with Barry on a regular basis to discuss my reflections and potential assumptions. For example, Barry would often find some of the participants' comments very informative, yet I felt that they were insignificant since to me these described experiences that were also part of my everyday life. For Barry, these experiences often provided a look into a phenomenon that he, as an able-bodied person, knew very little about. Thus, everyday experiences for me became a great eye-opener for Barry, which in return became an even greater eye-opener for me. I began to see my life and that of students with physical



disabilities at university through a new lens.

My reactions from the interviews and findings

"[...]one thing that amazes me about this project is that I was able to discover life at U of T; my own, and that of others." (Susan Guenther, 2004)

The process of researching what it feels like to attend U of T as a student with a physical disability was a very exciting process for me. I wanted to see whether other students experienced U of T differently or if they felt as alone as I did in my continuous struggles.

At the beginning of the process I remember feeling an increase in my self-esteem and confidence in my own experiences while talking with the participants and reflecting with Barry. For the first time in my university student career, I was forced to take a step back, to reflect on and think about my experiences and those of the research participants. From the beginning it was evident that students brought with them powerful personal qualities which they used while learning how to navigate the system. They were also exceptional advocates within the student world for their own needs as well as those of others; and, lastly, they were fighters, taking on the student challenge and striving to bring about change.

"What strikes me is all of the energy that goes into running around and trying to sort out your learning experience, and its ongoing energy consumption, because things keep on changing very often." (Susan Guenther, 2004)

This point made me think about the energy we spend on simply being regular students. What was it that the students were doing at university in order for them to be able to learn like other able-bodied students?

"With university there is this attitude that you come here to learn, however, when you have a disability that totally changes. Learning is not done in isolation. Getting to be able to learn at university for a person with a disability takes guts, strength, and perseverance." (Susan Guenther, 2004)

As I continued to reflect on the energy consumption the participants were describing I grew awed at the strength that each of us brought with us to the process. It is very difficult for me



I knew I needed accommodations, but I did not want my disability to set me apart from other applicants.

to describe how much energy it takes to just get through one day, let alone a week, and for us to be at university for four, eight, and over ten years really meant something to me. Going to university takes a strong character, but I also knew that despite the barriers, we succeeded within our learning experience and liked going to school.

“Even with all of the challenges and adversities in our paths the impact on learning is that we are generally very happy with where we are and wouldn’t want to give it up for anything either.” (Susan Guenther, 2004)

This made me reflect on the previous literature and research on the experiences of university students, which largely tends to focus on the barriers we face and less on successfully navigating the system.

“Why is it that researchers show more interest in what students with disabilities at school in general feel like and not so much what they do? I am tired of always being looked at as a student who finds going to university ‘so hard’ and not as a student who is successful, manages to get assignments done on time, and who has goals in her life no matter what the barriers are.”(Susan Guenther, 2004)

Obviously we develop a drive to succeed within the system. Barriers always arise, attitudes come our way, but we still seem to manage because we have to and because there is meaning behind it, even if we sometimes grit our teeth and feel like smashing a wheelchair into a ramp/step in frustration. When one student spoke about what failing university would mean, I remember reflecting on the pressure we feel to participate as equals at university.

“My biggest achievement I think will be to have finished...it’s always been a fight...I don’t want people to say, “oh well, she’s disabled so don’t worry if she doesn’t get a good grade”... I don’t want people to think of me that way, I want people to be like, “why aren’t you getting better than a C?” or something...that’s what drives that fear, that if I did fail, nobody would care.” (J.M., 2004)

For those of us who live with disabilities, going to university fills us with a sense of pride. We feel proud of our accomplishments and how far we have come. Yet, because it can be a challenge for an academic department to understand our needs or for us to explain them before we can experience such a unique and unexplored territory like university, this sense of pride can become a conflicting dilemma. I felt this dilemma when I applied for the occupational therapy program. I knew

I needed accommodations, but I did not want my disability to set me apart from other applicants. The following journaled thoughts describe the conflict I felt.

“When I applied for the OT program I purposefully didn’t put that I had a physical disability on my application. Why? I don’t know. I wanted to know that I got accepted into the program because I was qualified. All of my undergrad, I spent so much time advocating and fighting for things that I needed and fighting for things that other students with disabilities needed. I was sick of it! No more fighting! I just wanted to be a student, like anyone else. And I certainly didn’t want my disability to be a reason for someone to pounce on my application. Then I would have never known why I was accepted into the program.” (Susan Guenther, 2004)

A struggle with identity is definitely an underlying theme of going to university when you have a disability. You want to be a student like everyone else, but you also recognize that you are different. One participant described how they “came out as being disabled a lot more than in high school.” I too remember beginning to accept my disability when entering university. As I reflected on the participant’s statement, I felt that gaining independence and a strong sense of self needed to be a crucial step in order for me to succeed at university.

“Going into my undergrad I decided that it was best for me to get a scooter for mobility, something I never would have dreamed of in high school. I also needed to learn very quickly what my needs were and what my disability meant to me and to others. I was on my own here, and not knowing who I was would have isolated me quite quickly from my environment because I would have felt so intimidated and out of control...Independence becomes a necessity in order to teach and raise awareness about who we are. We need to work hard at taking the fear away of others, but more importantly take the fear away within ourselves. Only that way can our role at university take shape.” (Susan Guenther, 2004)

When I began this pilot study, I hoped to find an opportunity to discuss the impact of the participants’ school life on their life at home and vice versa, since this was a very important experience that I struggled with on a daily basis. Although the participants did not share many experiences of what they did aside from school and how this impacted their learning, I still journaled my reactions because they were an important part

My motto remains the following: that even though attending university with a disability seems difficult, it is by no means impossible.

of how I dealt with the process.

“When I sit in class and we are talking about an assignment my mind starts to race, ‘how am I going to do this, who am I going to talk to about this, what’s the first step for me today, tomorrow?’...For me it’s always like ‘do I need to take my meds tonight and if yes I know it takes about 2 hours, so what am I going to feel like doing when I am done? When will I be home? Who should I go talk to about getting my library articles?’...some days I feel overwhelmed because I need to take care of myself, but I also have to get my work done.” (Susan Guenther, 2004)

This journal entry also brought up feelings about my struggles with the need for assistive technology and how it sometimes enables me and also hinders me. Accommodations and assistive technology at home rather than at school played a huge role in getting me through my studies and preserving my energy, as they did for the other participants. As I reflected on the role of assistive technology, I wondered what accommodations actually mean to the people who use them.

“Figuring out how to use my laptop and my wireless network set-up wasn’t so easy. I ended up spending hours of frustrating trials in making things work, having people tell me what to do over the phone, or paying technical help to set things up for me twice! For what? If I would have just sat at a desktop that was already set up, I wouldn’t have wasted all of this time and money...even though it would have cost me a lot of energy and pain. So, yeah, in this case, if I wouldn’t have eventually figured the system out on my own, I would have abandoned it quite quickly. Theoretically, it made a lot of sense. Functionally, it made my life miserable.” (Susan Guenther, 2004)

During this research project I often thought about what made sense in theory and what worked functionally. Accommodations will always change how a person interacts with their environment. They will enable the individual by providing them the crucial adaptation they need to function with greater independence and ease, possibly allowing the individual to participate in a learning process that they otherwise could not participate in. But, accommodations will also hinder the individual by requiring them to change their learning process from that of able-bodied classmates (e.g., planning how to achieve their learning outcome with the accommodation or when the accommodation is available, etc.) Therefore, although accommodations greatly assist students with dis-

abilities in their learning, they may not become the full solution that they were intended to be. When one participant talked about using a sighted guide at a conference to get from point A to point B I couldn’t help but compare it to my experiences with using a librarian to photocopy journal articles for me. Keeping the goal of being able to learn in mind, a sighted guide may walk by posters at a conference not knowing that the person with low vision would benefit from reading them, just like a librarian would go into the stacks for me and photocopy the articles I requested out of volumes of journals that may also contain other articles of relevance to me that I might have discovered by flipping through them myself. This point is not meant to illustrate that accommodations are poor; it illustrates how different the learning environment of a student with a physical disability becomes when they rely on accommodations to access their environment.

Concluding thoughts: What the research process meant to me

Journaling my reflections certainly became a very important part of the entire research process. I became aware of my presence in the overall inquiry and analysis, and became more aware of my own voice and my unique and powerful story. Throughout the project and interviews, I began to better appreciate and understand the important role our stories play in raising the awareness of the general university population. As a student with a physical disability, meeting challenges and attitudes gets you involved; you start to fight and negotiate to gain a voice; you work on getting accommodations; then you’re able to begin the process of learning. Although it may appear that attending university with a physical disability is challenging, my motto remains the following: that even though attending university with a disability seems difficult, it is by no means impossible.

When I entered university, I never thought about becoming actively involved in research. I had always interpreted it as difficult, time consuming, and something that I was not skilled enough to do; but after completing the first part of this pilot study I recognize research as important and fun. I thoroughly enjoyed my personal and professional growth as part of the process. Barry’s questions and observations, coming from someone with little knowledge of the lived experience of students with disabilities, contrasted with my taken-for-granted experiences and comments on the lives of the student



I would have liked to spend a day on a campus with a checklist and a follow-up occupational therapy appointment to see what it was like to go to class, go to professors' offices, access the library and residences, etc.

participants. Barry was the first person to encourage me to use my insights into my own story, to seek others with a similar tale, and to devise a way to study the phenomenon of attending university with a physical disability and so help students, educators, and service providers gain some insight. This process in particular was very important in my development as a confident occupational therapist. Throughout my learning as part of the occupational therapy program, I found myself struggling greatly with the notion of what was “sharing too much” about my experiences and what was “sharing too little.” I felt that as I began to study within the program, I brought with me a unique understanding of the powerful influence of occupational therapy in enabling a person with a disability in daily life. This was not a notion that I needed to recognize or learn about, but it was a notion that I needed to reflect upon and understand from an angle that supported the practice of occupational therapy with theory and clinical reasoning. This shift in my process of developing as an occupational therapist was greatly augmented by this pilot study, which helped me shed my fear of not reflecting enough on my experiences and integrating this experience with the baseline skills of a confident and competent health-care professional.

As we move into the next phase of the project, I am excited that other universities and students in the area have heard what we are doing and have expressed interest in participating. There is a need for this type of research and, being a person that has been mentored by so many people, it feels empowering to develop the skills to begin to mentor others and empower other students by validating their experiences and providing them with a voice.

When I planned to enter university, nothing was available to help me to physically and emotionally prepare for the struggle that lay ahead. I would have liked to spend a day on a campus with a checklist and a follow-up occupational therapy appointment to see what it was like to go to class, go to professors' offices, access the library and residences, etc. It would have given me a good idea of my mobility needs on campus, my energy levels, need for attendant care or buddy system, and to plan the help and support I would need within this fast-paced and largely unsupportive environment. I certainly would have appreciated a discussion about energy conservation and strategies of dealing with stressful situations

related to the barriers I faced on a daily basis. How often did I find myself stuck outside of a building in front of a door or a step that administrative staff had told me was accessible? The stress often emotionally scarred me for days or even weeks and I found myself crying a lot and feeling ready to give up for periods throughout my studies. Facing such stress on a daily basis challenged me greatly, and I would have liked to receive more support in learning how to advocate for my needs without feeling guilty or weak, or a burden to others or to the system.

Overall, I am very grateful that I could develop my own research topic based on my experiences and struggles. It made the process a positive experience for me with the end result of adding my information to a body of research that will hopefully help other therapists and educators to become more aware of this area of needed practice, and to help make a greater difference in the lives of young adults with physical disabilities who attempt to transition into higher education.

Acknowledgements

I would like to acknowledge my research supervisor, Barry Trentham, for his guidance into the development and editing of this reflective article. I would also like to thank Dr. Bonnie Kirsh for providing a final review of the paper. In addition I want to acknowledge the Ontario Society of Occupational Therapists for funding the presentation of this research at the Canadian Association of Occupational Therapists 2005 conference and for recognizing the importance of this topic for the field of occupational therapy.

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Implications of universal design principles to vehicle design

Jan Miller Polgar, Lynn Shaw and Brenda Vrkljan

Universalism is a philosophical concept that places disability at one end of an ability-disability continuum and further suggests that most people will experience some level of disability in their lives¹. It has been posited as a philosophy that supports many of the values and beliefs of occupational therapy². Universal design refers to a set of principles, grounded in universalism, that guide product development and evaluation to promote access and use by a wide range of individuals³. These principles are applied in this paper to the design of vehicles and emerging technology such as navigation systems, with the assumption that this application will enhance the safety of vehicle occupants. Universal design principles are not intended to take into account other factors that influence the design process such as economics, safety issues, or environmental concerns⁴.

Universal Design Principles

Briefly, the seven principles of universal design include:

Equitable Use: The design allows equitable access for individuals with varying capacities in a way that does not create stigma.

Flexibility in Use: Access can be achieved in a variety of ways, e.g., with the right or left hand, while still retaining accuracy and control.

Simple and Intuitive to Use: Operation of the device can be completed easily without unnecessary steps. A device's use is obvious in its design.

Perceptible Information: Information is provided in a manner that can be perceived by users of different abilities. The device will support the use of alternate strategies or devices that aid perception.

Tolerance for Error: Sufficient safeguards are built into the device such that unintentional actions do not result in dangerous consequences.

Low Physical Effort: Design takes into consideration repetition of movements, body posture and position, and force required for effective use such that these elements do not exceed the capacity of a range of individuals.

Size and Space for Approach and Use: The area around or in which the device is to be used is sufficient to allow clear sightlines and comfortable reach and accommodate the use of assistive technology⁵.

Vehicle Use

To consider the implications of universal design principles to vehicle design, let's first consider the various occupations in which people engage when they use a vehicle. Of necessity please note, this description is a very simplistic account of a very complex and dynamic task. Users enter and exit the vehicle, opening and closing the door. Once inside, seats, mirrors and other controls are adjusted and seatbelts are fastened (and ultimately unfastened). Drivers control the vehicle using the steering wheel and pedals, control various functions of the vehicle such as lights and windshield wipers, and signal their intentions through the use of indicator signals. They must perceive important information conveyed by the vehicle, such as speed and fuel consumption, and see out the windows to gather visual information from the external environment.

The application of universal design principles will be considered with respect to the visual, cognitive and physical demands of vehicle use and will apply these to both existing and emerging technology such as heads-up displays or on-board navigation systems. Our assumption when describing a vehicle that incorporates universal design principles is that the driver has the capacity to be safe behind the wheel.

Visual Considerations

Both drivers and passengers must be able to retrieve visual information from both within the vehicle and the external environment. Windows and mirrors should be of a sufficient size to enable good sightlines and minimize blind spots. Glare was mentioned as a hazard by participants in a qualitative study on the use of vehicle safety features⁶. Visor extensions were used to minimize this hazard. Within the vehicle a number of considerations must be made to maximize the likelihood that visual information is presented in a way that is readily perceptible. Information that is of key importance (e.g., speed and fuel consumption gauges) should be placed within the central visual field just below eye level to minimize any distortion that occurs when the driver shifts visual attention from distant to near objects. The visual display should be of a sufficient size with an appropriate colour contrast to facilitate easy reading by individuals with varying visual abilities. The amount of information provided should be minimal to limit the scanning required.

continued on page 32



Universal design principles to vehicle design, continued from page 31

Physical Considerations

Participants in the qualitative study mentioned above were overwhelmingly concerned with the effective use of seatbelts⁷. Many indicated that the seatbelt did not fit properly or comfortably and consequently some did not use them, while others used modifications (e.g., additional padding) to lessen the discomfort. Given the well-supported role that seatbelt use plays in reducing death and injury in motor vehicle crashes, design of seatbelts to accommodate a variety of body shapes and sizes is essential. More adjustability is needed to ensure that the seatbelt sits properly on the user's neck and pelvis and fits comfortably around their girth.

Fastening and unfastening seatbelts is another problematic issue for some drivers. The force required, the variety of styles used and difficulty seeing the attachment point are all physical concerns identified with the use of seatbelts. More standard means of coupling the seatbelt components are now found on later model vehicles. However, issues relating to the force required to fasten and particularly unfasten the seatbelt need to be addressed. These issues have particular implications for individuals with motor or musculoskeletal impairments that cause weakness of the hands or imprecision of hand and upper extremity movements.

Entering and exiting a vehicle is another task that can limit a person's ability to use a vehicle. Application of universal design principles would result in a vehicle in which entry and exit are facilitated by the height of the vehicle, pivoting seats, and a power assist mechanism to open and close the vehicle doors.

The design of vehicle seats has changed dramatically over the past several years, and manufacturers of these products are paying more attention to issues related to varying body shapes and sizes and the position in which the seat places the vehicle occupant⁸. The ideal seat is easily adjusted and puts the occupant at the proper height, distance and position to enable safe driving as well as other occupations.

Location and activation of controls for devices is an important ergonomic consideration. Here universal design suggests that individuals with restricted range, power, and accuracy should be able to access these controls in a manner similar to individuals without this level of ability.

Cognitive Considerations

Much attention has been given to various cognitive issues related to driving. Driver distraction is a huge issue and stems from any number of distracters such as children and other passengers,

coffee drinking, operation of features not related to driving such as temperature adjustment and, of course, cell phone use. In terms of vehicle design, the use of devices within the vehicle should not distract the driver from the primary task of driving. The universal design principle of use being simple and intuitive is most applicable here. Devices and controls within the vehicle should be simple to use. Work in other areas of assistive technology has suggested that devices that are too complex to use or to learn to use are more likely to be abandoned⁹. A device that requires too many steps to activate or control has the potential to distract the driver, resulting in a hazardous situation.

The design of a vehicle can promote ease of use and safety for consumers when attention is paid to various ergonomic considerations. Application of universal design principles to vehicle design is one means of promoting safe transportation for a wide range of users.

Acknowledgement

The authors' research is supported by AUTO21: The Automobile of the 21st Century, a Canadian Network of Centres of Excellence.

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