



**FREE BOOK – How to Create a Trust**

**February 2008**

**by Laurette Yelle**

The Voice of the Cerebral Palsied of Greater Vancouver received a grant from the Law Foundation of BC to update our popular resource guide, **How to Create a Trust**, a book for British Columbians receiving PWD Benefits (and their families). You can now order copies of it for yourself or – if you are a member of an organization – for your clients.

If you are receiving PWD Benefits and you suddenly come into money (for example, through an inheritance or court settlement) you can lose your benefits – including medical coverage! To help avoid this situation, you can put that money into a trust. This book is the first step to finding out what a trust is and whether it is right for you. **How to Create a Trust** will help you be well-informed so if you decide to create a trust, you will be able to use your time with a lawyer more efficiently. (Families with children who have disabilities will also want to learn about trusts.)

There are two ways to pick up copies of the book:

(1) visit the Voice of the Cerebral Palsied of Greater Vancouver and pick up as many books as you need for **free**, Monday – Friday, 12:30-4:00pm, or,

(2) send a cheque for **\$4 per book** (to cover our postage fees) and we'll mail them to you. Make cheques out to the VCP and send to: The Voice of the Cerebral Palsied of Greater Vancouver, #103–577 East 8<sup>th</sup> Avenue, Vancouver, BC V5T 1S9. Remember to give us your full mailing address and indicate how many Trust books you'd like.

**\*\*PLEASE NOTE: How to Create a Trust** is aimed at anyone receiving PWD Benefits, not just people with CP. We welcome orders both from individuals, and from organizations who wish to distribute copies to their staff, clients, and membership.

## **HandyDART to Undergo Major Changes**

**By Laurette Yelle**

In early 2005, TransLink started the “Access Transit Project” which was a major review of the entire transit system, including both the public buses and handyDART, or “custom transit.” The goal of this review was to give people the broadest range of travel choices by working toward a 100% accessibility in the public transit system, and improving the way that custom transit is operated.

The results of this review are contained in a document entitled, “Access Transit: You Spoke, We Listened.”

The recommendations in this report regarding handyDART are as follows:

1. Create an Access Transit Office within TransLink to make using custom transit simple and to oversee the implementation of the recommendations in this report. It will provide a single contact point for users and manage eligibility, registration, bookings and information for handyDART. It will also monitor system performance, review unresolved complaints, provide travel training for the entire transit system, and standardize and integrate service across the whole region.

For example, currently, each area within the region has its own handyDART provider with its own hours of operation and eligibility

requirements. This situation can make travelling across boundaries challenging.

A Users’ Advisory Committee will be struck to work with the Access Transit Office to ensure that customer needs are considered in the planning and delivery of services.

2. Increase the number of trips and service hours to provide longer, more consistent hours of service and more non-medical trips. In 2008, handyDART service will have 30 more vehicles offering 60,000 more hours of service and 130,000 more trips.
3. TransLink should work with the provincial government to find ways to better manage demand for medical and social service trips so there is more service available for other kinds of custom transit trips.

Because of a growing senior population, there is an increasing demand for medical bookings, including on-going bookings for dialysis. People are finding it increasingly difficult to book trips for social outings because the spaces have been filled for medical trips which have priority over social trips.

4. Reduce the number of service areas from eight to three. The recommended service areas are: South of the Fraser, Pitt Meadows and Maple Ridge, and North Shore/Richmond/Burrard Peninsula (West of Pitt River).

The rationale behind reducing the number of service areas is to decrease the amount of money spent on administration and lessen the need for riders to cross boundaries. It will also mean that there will be a huge change in operators.

5. Give existing service providers and their employees the opportunity to form new entities to deliver services within the new service areas starting January 2009. To facilitate this transition, existing contracts should be extended to December 2008.

Current operators will have to decide whether they want to bid on the expanded areas on their own, join with other operators to submit joint bids, or not participate at all. Added to the mix is interest shown by other companies, especially large bus companies, to submit bids. The date for submitting Expressions of Interest was January 11, 2008. A formal Request for Proposals will be issued in mid-February with proposals due by May. The new operators are to be in place by January 2009.

6. Make service easier to use by creating a more responsive and flexible booking system. This system should offer shorter advance booking times, extended call-in service hours, online booking and trip management support, and better in-vehicle communications with drivers and passengers.

7. TransLink should establish permanent storage and maintenance facilities for custom transit vehicles by 2010 and actively seek and test better vehicles to improve the comfort of passengers.

This report was issued in the summer of 2007. The recommendations will be phased in over the next three years and reviewed in 2010.

As a point of interest, since this report was issued, Translink has changed its name to the South Coast British Columbia Transportation Authority.



### **Airlines ordered to drop extra fares for the disabled.**

January 10, 2008  
*CTV.ca News Staff*

Canada's major air carriers have been ordered to offer the disabled travelers same fares as everyone else. Under a Canadian Transportation Agency ruling, travelers who need additional seating because of their disabilities will no longer have to pay more than a single fare for domestic flights. Air Canada, Air Canada Jazz and WestJet have one year to bring in a "one-person-one-fare" policy for people with severe disabilities – including the

severely obese – who require two seats to accommodate them.

The ruling also applies to disabled people who need a medical attendant seated with them on flights.

The CTA stresses that the ruling applies only to people with severe disabilities.

“It’s not for persons without disabilities who might, for example, feel uncomfortable in an aircraft seat,” CTA senior communications advisor Jadrino Huot told CTV Newsnet on Thursday. The CTA estimates the new policy will cost Air Canada about \$7 million a year, and WestJet about \$1.5 million a year. That amounts to about 77 cents a ticket for Air Canada, and 44 cents for WestJet.

But Huot told Newsnet it would be “very hard” to predict exactly what will happen with air ticket prices, as it’s up to the individual air carriers on how they would implement the one-fare policy.

“Air carriers will be the only ones that could answer that question” said Huot. A complaint was brought against Air Canada, Air Canada Jazz, WestJet and the Gander International Airport Authority in 2002 Joanne Neubauer, Eric Norman, and the Council of Canadians with Disabilities.

Neubauer said the ruling means that she can finally hold her “head up high”.

“I’m an equal Canadian now” she told CTV News.

Linda McKay-Panos, who had fought for more than 10 years for the obese, was unable to fly because she couldn’t sit in one seat.

“I’m really looking forward to being able to say to my husband, ‘let’s go on a

holiday where we don’t have to drive. We can actually fly somewhere.”

### **‘Slippery Slope’**

Some in the airline industry, meanwhile, are complaining the industry is now faced with making some complicated decisions, including who is obese enough to qualify under the ruling.

“They are imposing new regulatory obligations which also add to the cost of doing business” Air Transport Association policy vice-president Fred Gaspar told CTV News.

“Our check-in agents are not nurses. Our flight attendants are not doctors, so we think it’s a slippery slope.”

Most Canadian bus, ferry and train companies already have policies to accommodate disabled travelers.

People travelling with attendants or who have equipment or mobility aides that take up more than one seat do not have to pay additional fares while on board most buses, trains or ferries.

Currently, Air Canada offers a 50 – per cent discount for some attendants travelling with disabled customers on flights within North America.

The CTA’s decision could have far-reaching implications as Canada’s population ages. The case has also sparked the interest of advocates for obese travelers who are often charged extra fares for additional seating.

In December 2001, the CTA ruled that some obese passengers could be considered disabled. In its ruling, the agency said complaints issued by obese travelers should be considered on a case-by-case basis.

*With a report from CTV’s Roger Smith in Ottawa*

## Shanti's Sister

reviewed by

**Jonn Olldym**

Gabrielle Miller has a "blast" playing Lacey Burrows, the sweet, strong-willed proprietor of The Ruby Café on the CTV comedy, *Corner Gas*. But her real-life role as younger sister to Shanti, who has cerebral palsy, has been Miller's most rewarding.

The Vancouver based actress heads a group of family and friends who serve on her sister's "microboard" – the Shanti Miller Friendship Society. Shanti's microboard was the first one created in BC in 1989 when she was then 19 year old, and about to be institutionalized. Shanti uses a wheelchair and requires 24 hour care.

Now, Shanti, 37, is thriving, with an active social life, and lives in her own home in Vancouver, with round – the – clock care. She has a circle of family and friends who she visits regularly.

Shanti loves to socialize. She likes going to the movies, restaurants likes to watch sports, having parties, and she really likes going out dancing. Gabrielle says that having a microboard has allowed her sister to live her life the way she wants to, with a freedom she would not have known in an institution.

Gabrielle is one of six who manage the funds for Shanti's support, help find and train her support staff, and help organize work schedules. Gabrielle and the others on the board involve Shanti in the

decisions about her life, by talking to her about her goals for the year, budgets, etc.

Having grown up with a sister who had so many challenges has been a huge inspiration to Gabrielle. She is still finding out ways that her sister has affected her. Gabrielle says that Shanti can get a room of strangers talking more quickly than anyone Gabrielle knows. To Gabrielle, Shanti's love of others is a gift.

When not shooting *Corner Gas*, Gabrielle is a spokesperson for the Vela Microboard Association ([www.microboard.org](http://www.microboard.org)), whose staff provide support for the now 500 microboards in B.C.

*See the January 2008 Reader's Digest to read the full article written by Robin Roberts.*



### **Report on the "Emergency Planning for People with Disabilities Workshop 1".**

**by Jonn Olldym**

An explosion has happened in your community, and the whole area around you, including you're the building you live in, is affected. Fire is raging through the buildings, including your own.

Transportation is extremely limited, and telephone lines and electrical lines are down. You are in your unit, in your wheelchair, and care attendants are not

able to get to you to help you. What do you do?

The Emergency Planning for People with Disabilities Committee held a workshop on just what to do during any kind of major emergency. The Committee's co-chairs, Karen Martin from the B. C. Coalition of Peoples with Disabilities, and Karen Van Biesen, of The Voice of the Cerebral Palsied of Greater Vancouver, co-chaired this workshop that was held on January 23, 2008. This workshop was the first of 3 all-day workshops being planned that center around enabling disabled people to properly prepare for any kind of emergency or disaster. Funding for these workshops is being provided by the Provincial Ministry of Health, and the Public Health Agency of Canada. This first workshop, which took place at the Morris J. Wosk Center for Dialogue at Seymour and Hastings, in downtown Vancouver, was on the planning and preparedness of emergencies. The other 2 workshops, one on response and one on recovery, will be held at the same place.

The workshop was organized into five small groups; and the participants were assigned to one of each of the following: Communications, Medical Supplies and Supports, Personal and Disability Organizations Preparedness, Transportation and Training.

Approximately thirty people attended the workshop, some coming from the Emergency Preparedness and Planning arm of the Provincial, Regional and Civic levels of government; some from the health and social service agencies

servicing the disabled community, and some from the disabled community itself. Each of the small groups was given a list of 8 – 11 questions to discuss, and make recommendations on them to the afternoon plenary session. There were 2 small group sessions in the morning, which dealt with the initial set of questions around research and planning for an emergency / disaster, and the last 3 questions dealing with appropriate actions to be taken, and by whom, were dealt with in the afternoon small group session.

There was time during the breaks and lunch to mingle, network, and share ideas that were presented during the small group discussions. As well, there were report back sessions, in the morning and afternoon, where the small groups presented the information and recommendation each of them generated. A summary of the actions that need to be taken will be prepared as part of the report that will be produced after the workshops are finished. This report will be made available to the disabled community through the Emergency Planning for People with Disabilities Committee. For information on this forthcoming report, and any information on the work of this committee, please call Karen Martin at 604-875-0188, Karen Van Biesen or myself at the Voice office.



**Imagine Leadership 2008: A leadership retreat on Creating Personalized Supports that are designed and governed by the people who rely on them.**

**by Jonn Olldym**

This retreat was held on January 11 – 13, 2008 at the beautiful setting of Edenvale Retreat Center, in Abbotsford, BC. Thanks to funding through the BC Association of Community Living, who sponsored me, for which I'm very grateful, I was able to participate in this event.

The main speaker at this retreat was a Dr. Michael Kendrick, an independent consultant in human services and community. As well, there were two others presenting at this event, a Janet Klees, Author and Family Coordinator of Deohaeko Support Network in Toronto, and Linda Dawe, a respected Parent Leader, and a founding member of the Deohaeko Support Network. Together, they offered those attending a unique forum for learning; dialogue and the chance to take action to better support families and people who rely on services in British Columbia.

Families and individuals have sought out the creation of Microboards for themselves, or their loved ones. These Microboards are a means of being in charge and taking control of their personalized services. This event presented another option of "family and user governed service arrangements" that could serve as a possible means of meeting people's needs.

The weekend began with a time of socialization and ice breakers on Friday evening, giving people a chance to "wind" down from the day and the travelling to the Retreat Center in Abbotsford. On Saturday and Sunday, Michael, Janet and Linda led us on a "tour" of the many dimensions of quality within family guided services, and their components. There was a determined effort to present this material to us within the framework of personalized safeguards as a means of managing personal vulnerabilities and issues that were related to how the delivery of quality in individualized services could be guaranteed.

Janet and Linda have been involved with Deohaeko for over 17 years, and they shared from their experiences with this intentional community of families and their disabled adult children. They shared the guiding principles of this community, what they have learned in the process, and how important it is to have clear, strong principles be the guide to work within the network, from the beginning to now. They described the creation of "circles of friends" – sustained personal networks (and the processes involved in building these relationships) showing us just how integral these circles are to the aims of supporting a well-lived life within the context of their community.

This event gave me a new understanding of what's involved in this kind and level of care; and, as well, just how the principles outlined at this event could be incorporated into the BC picture, without copying the Deohaeko community exactly.

**Disability  
Arts  
Symposium  
- at the  
Gallery Gachet**

**by A. J. Brown**

On Friday, January 25, I attended a workshop for artist organizations for artists with disabilities. It was called the Disability Arts Symposium. It was at the Gallery Gachet in Vancouver. They want to unite artists with any type of disability working in any medium. They are creating a disability arts network across BC.

In 2006 artists and organizations came together to Vancouver to discuss the needs and struggles of oartists with disabilities in BC. Now 18 months later, the BC Regional Integrated Arts Network (BRIAN) invited the community to get together for an inspired day long event.

'Integrated arts practitioners' were invited to hear from pioneers and visionaries, create connections, debate ideas, and enjoy great food. While we work in different disciplines (theatre, media, visual arts, etc) many of the issues are

the same. We came to share and understand what unites and divides us, where we need equity and access, funding, overcoming labels, confronting marginalization, and realizing peer support.

The day's event included panel discussions and presentations that addressed:

1. Does a 'disability arts' label help or hinder artists? There were points of view from Australia, the UK and Canada.
2. Report back on the results of the 2007 disability arts sector consultations, and plans to launch BRIAN as a provincial resource for urban and rural artists.
3. Making the arts accessible for both audiences and on the stage.
4. Advocating for inclusion of disability arts in Cultural Olympiad programming.
5. Video messages about rights and citizenship.
6. How would BRIAN operate as a network in BC?
7. Establishing a Mentorship nd Commissioning Fund for BC artists with disabilities.
8. Open Space – participants can self-organize into a hot topic.

There were three panelists: Bruce Gladwin, Wendy Hollo, and Geoff McMurchy.

Bruce Gladwin is the artistic director of Back to Back Theatre, a pioneering Australian contemporary theatre company, with a full-time ensemble of five actors with intellectual disabilities. The organization has become one of Australia's leading creative voices, focusing on moral, philosophical, and political questions about the value of individual lives.

Wendy Hollo is the Executive Director of Edmonton's Nina Haggerty Centre for the Arts and an educator on self-advocates learning and using their rights. Wendy was joined by some of the Centre's Lead Artists including Ull Rossier.

Geoff McMurchy's cultural leadership comes after a 30 year process of politicization as an artist with a significant spinal cord injury. He is now Artistic Director of the Society for Disability Arts and Culture, which strives to empower artists and performers with disabilities to correct misrepresentations by creating their own narratives, and to bring disability-controlled narratives to wider audiences.

Taken from the brochure.



**The Unruly  
Salon:  
Presented by  
Green College,  
at UBC,  
January 12  
to  
March 29, 2008.**

**by A. J. Brown**

In the context of a burgeoning disability arts and culture movement in Canada and internationally, the Unruly Salon series is an historical first at UBC. Drawing from both internationally renowned scholars of disability studies and professional artists from the visual, performing, musical arts sectors, the Salons will demonstrate a belief that the pursuit of equality and inclusion is a cultural task as much as it is an academic and political one. The series promises to further the discourse on diversity, humanity and civil society; contribute to a fundamental reshaping of the disability narrative; challenge ideas of 'global citizenship'; and work to realize the full inclusion of all people.

[www.unrulysalon.com](http://www.unrulysalon.com)

## **Pointing it Out**

**by**

**Jonn Olldym**

The Augmentative Communication Community Partnership – Canada is a Canada-wide non-profit organization that supports people who have communication disabilities and who use Augmentative and Alternative Communication (ACCPC). This organization provides research, education and resources to its members and others that need or can make use of its services. As well, this organization focuses on social justice issues for its constituency. The following information is about an instructional DVD and booklet called “Pointing it Out”, directed and produced by Barbara Colier about safety for people who have communication disabilities and who communicate using displays and devices. It is taken directly from their web site, ([www.accpc.ca](http://www.accpc.ca)) and is quoted in its entirety here.

Pointing it Out is about safety for people who have communication disabilities and who use augmentative and alternative communication (AAC). AAC includes

letter, word or picture boards and devices that speak out messages.

Pointing it Out contains:

A DVD showing people who use AAC sharing their views on ways to increase their safety.

A booklet with information, assignments and resources.

An audio CD of the booklet.

Funding

ACCPC is grateful to The Ontario Trillium Foundation for funding this project. The Ontario Trillium Foundation is an agency of the Ontario Government and is one of Canada’s leading grantmaking foundations. The Foundation provides grants to eligible charitable and not-for-profit organizations in the fields of arts and culture, sports and recreation, the environment and human and social services.

Partner Organizations

ICAN: Independence Centre and network, Sudbury  
Ontario March of Dimes, Hamilton  
The Gage Transition to Independent Living



## Augmentative Communication Community Partnerships – Canada

### Pointing it Out

#### *Safety for People who use Augmentative Communication*

Instructional DVD and booklet

### ORDER YOUR COPY NOW!

#### *About Pointing it Out*

Directed and produced by Barbara Collier, Pointing it Out is a DVD and booklet about safety for people who have communication disabilities and who communicate using displays and devices.

Eight adults who use augmentative and alternative communication discuss issues and make recommendations.

#### *The Product*

Cost: Professional and organization rate: \$75 US or CAD • AAC user / family: \$60 US or CAD  
(Cheques only. Please make cheques payable to ACCPC).

For information and to download an order form:  
[www.accpc.ca](http://www.accpc.ca) or email: [accpc@sympatico.ca](mailto:accpc@sympatico.ca)  
Address: ACCPC, 131 Barber Greene Rd.  
Toronto ON M3C 3Y5 Canada

#### *The Audience*

- Adults and youth (15 years and up) who use AAC and who are interested in their rights and safety.
- Families, clinicians, teachers, counselors, disability advocates, attendants, health care and legal professionals, police and others who work in community services.

*"Pointing it Out makes a unique contribution in that it is by people who use augmentative and alternative communication (AAC\*) and is for people who use AAC. Professionals will learn a great deal by listening to the perspectives and recommendations of individuals who use AAC. This is definitely a "must have" resource for anyone who supports people who use AAC!"*

Janice Light, Ph.D., Penn State University

\* AAC refers to communication displays and devices.  
Many people who have communication disabilities use AAC to communicate.

Augmentative Communication Community Partnerships – Canada (ACCPC) is a Canadian non-profit organization that focuses on social justice issues for people who have complex communication disabilities and who use augmentative and alternative communication (AAC) systems.

For information about accpc and its projects see [www.accpc.ca](http://www.accpc.ca) or call 416-444-9532.



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Editor's Comments:

**Tone of Voice** is the newsletter of **The Voice of the Cerebral Palsied of Greater Vancouver (YCP)**. The views and opinions expressed in the **Tone of Voice** are not necessarily those of the Board of Directors, The Newsletter Committee, or the Production Staff of the YCP. The articles presented herein are meant to be thought-provoking and stimulate dialogue. **Tone of Voice** is a forum for individual creativity and the generation of ideas from within the Cerebral Palsied community of British Columbia. This is your opportunity to share information and insights and to introduce issues and topics you feel should be brought to the attention of the Cerebral Palsied community and the general public. We invite your comments and criticism of any of the articles published here. **We hope that you will contribute articles to share with other readers. We want your stories, letters, announcements, poetry, graphics and cartoons.**



Please submit your material to:  
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