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From the Executive Director

Hello Everyone,
As you can see, Vela's Microboard Newsletter has a new look and name. The Communications Committee at Vela has been working very hard over the last several months to upgrade both the Newsletter and the Web site. It is our intention to ensure that the information provided through both sources is maintained in a timely fashion and is of relevance for the Vela Microboards in B.C.

Vela has established an editing team for VelaVision. If you have any ideas, articles, or feedback, please contact **Helen Stovell**, Vela's Office Manager at: (604) 575-2588 or via e-mail at: **info@microboard.org** and she will be happy to share your information with the rest of the members of the Newsletter's editing team.

The web site also sports a new look. More and more people around B.C. are looking to our web site for basic information on Microboards as well as specific information on particular issues relevant to established Vela Microboards. The web site is rapidly becoming a source of information for people from other provinces and countries looking to learn more about the concept and philosophy of Vela Microboards.

As a result, we are working on updating our look and ensuring that the information maintained is current and relevant. There are now, or soon will be, sections including: an introduction to basic information on Vela Microboards; a list of people involved at Vela, including board, volunteers and staff; frequently asked questions;

new projects 2001; a copy of *Vela Vision*; upcoming events of relevance to Vela Microboards; links and resources; and how you can help.

We are very fortunate to have the expertise of **Glyn Townson** managing our website. Glyn can be contacted at:

webmaster@microboard.org.

If you'd like to offer ideas or information for our website, please forward your suggestions to our committee liaison, **Jeanette Holder** at **jeanette@microboard.org.**

A reminder to all, both *Vela Vision* and the website are a reflection of the Vela Microboards and we welcome your feedback, stories and information for inclusion. We'll look forward to hearing from you.

Vela is very pleased to state that we have successfully applied for and received two grants for new initiatives. This will help us expand our supports to existing Vela Microboards as well as extend our work to assist people not currently able to access supports through Microboards.

The first grant is for one year from the Law Foundation. This will allow us to review policies, regulations, and legislation that are of relevance to Microboards. We will then translate these into plain language, and provide that information in a binder available to Vela Microboards. We will also be touring the province with the information to discuss and present the summaries.

The second grant from the **Vancouver Foundation** is for a three year project. This will allow Vela to explore partnerships with other provincial organizations representing people that have not had an opportunity to access supports

through a Microboard. In the first year we will be establishing the parameters for the project as well as meeting with potential partner organizations. We hope to have the first partner organization identified and have the work with their constituents well under way by the end of the first year. We are all very excited by the potential of this project.

We will keep you posted on the progress of both projects through *Vela Vision* and the website. And again, we will welcome your support and input.

Within B.C., there have been several new initiatives for Vela and the Microboards to address. The wage lift for non union services has been trickling down to the Microboards. While this has been most welcome, it has been a challenge to determine exactly how the wage increases can be passed on to the Microboard employees. The benefits portion of the increase and how it can be applied, is still to be sorted out.

Vela has been working closely with the Provincial Monitoring Group to develop a monitoring tool that will be useful for Microboards. Ten Vela Microboards through out B.C. volunteered to participate in the pilot process for the new tool. By all accounts things have been going well. Vela, the Microboards and the Provincial Monitoring Group have learned from this undertaking. It is our hope to have some written feedback on the tool and generally, on the project, available for you by the summer.

For many Vela Microboards, funding is now being accessed from two sources. The Ministry of Health now provides some funding for people that have health needs as well as a developmental challenge. In many instances this has made cost sharing of supports a positive

outcome. However, for many this has

been a confusing process. Unlike the Ministry for Children and Families, funding from local Health Authorities differs significantly from region to region. This means each region determines it's own budget priorities and spending patterns. As a result, each region must be negotiated with as a separate entity and precedent from other regions is irrelevant. Needless to say, this has presented some challenges.

On the International scene, as a result of presentations by representatives from Vela and several Vela Microboards at the Self Determination conference held in Seattle, Washington, July, 2000, Vela has experienced an expanded demand for information and support from much further afield.

We have provided information to interested people in Australia, England, Scotland, eleven states in the U.S.; Ontario, New Brunswick, Quebec, Saskatchewan and Alberta. Currently we are in ongoing dialogue and supporting initiatives in Northern Ireland, Virginia, Utah, and most recently, Tennessee.

The tremendous successes of the individual Vela Microboards in B.C. have led to this expanded interest. You have much to be proud of!

We encourage you to become involved. Please let us know if you would like to assist with upcoming issues of the newsletter and/or with the maintenance of information on the website. We will look forward to your feedback on *Vela Vision* and on the updates.

Best Regards,

Linda Perry,
Executive Director
Vela Microboard Association of B.C.

Ten Years in Retrospect

It is truly amazing all that Vela and families have accomplished in just over a decade. As I look at the map of BC in Vela's new office, which shows the location of Microboards, it is clear they have taken root in every corner of the province. From its humble, but inspired beginnings 10 years ago, more than 150 Microboards have been developed through Vela! Families in BC are more included and empowered now than ever before. Microboards have been accorded a newly expressed legitimacy as a service model within the management ranks of the public service. As well, the concept is broadening to other sectors of the population. Two highly respected Foundations have recognized the value of Microboards and have approved grants for Vela. There is also growing interest across Canada and internationally. Microboards are seen as a highly successful model of Individualized Funding.

But it hasn't always been this way. The idea was first conceived in Manitoba, by David Wetherow, who has since moved to BC with his family. In 1989, while working for British Columbia Association for Community Living, advocating and supporting individuals and families, Stephanie Watson began researching innovative service models. On a shoestring budget with the generosity of Corrinne Zajac, then the General Manager of the Pacific Palisades Hotel, Stephanie worked to bring David Wetherow to BC. David spent 3 days with key people in the advocacy sector and in the public service. The seed was planted. Shortly afterwards, Vela Housing Society excitedly agreed to transplant and adapt the concept to BC. Before long, Vela's Board of Directors which included Connie Clark, Stephen Russell, Jean Bennett, Linda Perry and Stephanie Watson, collectively prepared a draft



proposal and submitted it to the Ministry of Health. Their advocacy and salespersonship prevailed; they were steadfast. A contract was soon negotiated and signed.

This first approval of a new and to some, a very radical, pilot project to support 3 people in the Lower Mainland was tentative. The Microboard service delivery model was completely untested. There was plenty of resistance and opposition was everywhere. Could families be trusted with taxpayer dollars? How could a parent still be a parent and also the vice president of a Microboard? And just what was a Microboard anyway - part of a computer? Through the vision of Vela's Board and the dedication of its first staff member, Linda Perry, the pilot project more than met expectations. It was meant to take approximately 18 months to complete, but well before completion and prior to any real evaluation, the project's contract was renegotiated and expanded to allow for more individuals to be served in this unique manner. Thereafter, referrals from individuals and families around the province rapidly arrived.

In 1990, the first contract between the Government of British Columbia and a Microboard was signed. The rest is history, permanently so. Hats off to the early leadership in Vela more than a decade ago and to the individuals who had the courage of their convictions. And a special acknowledgment to Wayne Doane in the Ministry for Children and Families who shepherded the original contract with Vela through thick and thin all these years.

Submitted by
Dr. Peter Melhuish,
Vela Board member

Job Posting

Description:

Research Assistant for New Project

The Vela Microboard Association requires a dedicated and talented individual to assist in the development of a Legal Education Manual for Microboards in BC. The contract will consist of researching the legal implications of legislation, codes and standards relevant to Microboards and translation into an easy to read format. The ideal candidate must be able to demonstrate excellent writing skills and should have a strong legal background. Understanding and familiarity of Microboards would be an asset.

This is a short term contract with a duration of 3-4 months and the candidate must be able to work with minimal supervision and in collaboration with an advisory committee. Please submit resumes along with a covering letter by April 25th to:

Vela Microboard Association
5686 - 176 Street,
Surrey, B.C., V3S 4C6
or by Fax at 604-575-2589

Contract to begin May 1, 2001

Vela's Holiday Season Potluck and Dance

On Friday, December 8, 2000, the hamlet of Port Kells, B.C. was rocking when Microboards from the lower mainland held a holiday season potluck and dance. More than 100 people from across the Fraser Valley and Vancouver enjoyed each others home cooking and good company. Glen, our conference karaoke and music man, was on hand to entertain us all.

Thanks to Bernice Doucet Ryan, the inspiration behind the dance. The evening was a great success and this event will hopefully be held annually. Who could miss seeing Brent Wilson cut up the dance floor!

Vela MicroBoard Association Conference 2001

Mark your calendars, the Vela Microboard's annual conference will be held at the Sheraton Guildford Hotel, in Surrey, B.C., **October 12 -14, 2001.**

Planning for the conference is underway and Vela encourages Microboards to contact the Vela office with your suggestions for topics and any issues you would like to see addressed in conference sessions.

Each year the conference is well attended by Microboards throughout B.C. It creates many opportunities for people to network with each other and provides information pertinent to Microboards.

The 2000 Vela Microboard conference featured presentations on a number of topics relevant to Microboards, including Representation Agreements, Employment Standards, the Provincial Monitoring Group and the Individualized Funding Project. The following is a recap of the important points given in these sessions and contacts should you require further information.



FAQ's

1) Can you do a microboard for children?

Absolutely. You can do a microboard for anyone, regardless of age or disability. In the Province of British Columbia anyone is able to establish a non-profit society provided you meet the requirements of the Societies Act.

2) Will the government let us do a microboard?

It is not up to the government to decide whether or not a society can be formed so long as it meets the requirements of the Societies Act.

3) Will the ministry give us money?

In British Columbia, funding and the willingness to fund varies from region to region. In B.C., there is no legal obligation to provide services. Part of the assistance the Vela Microboard Association provides is guidance and support around the negotiation for funding and services in the various regions.

Vela's New Projects in 2001

The new millennium marked ten groundbreaking and challenging years of Vela's development of Microboards in B.C. Vela now faces a new decade of strengthening existing Microboards and of exciting opportunities to bring Microboards and new possibilities to more and more people across Canada, and hopefully, around the world.

After the February 2000 Vela Board Retreat, Stephanie Watson was contracted to explore new



growth opportunities and ways to strengthen Vela's support to Microboards. Vela is facing the future with confidence and as the result of much creativity and hard work, Vela has received funding for two new projects. These projects will assist Vela in reaching more individuals and families seeking the Microboard model and will help both new and current Microboards become even stronger and more self sufficient with the help of useful, relevant and important information.



Vela has received funding from the Law Foundation of B.C. for a one year project to develop a Legal Education Manual and the delivery of regional workshops regarding legal issues that are of concern to Microboards (ie. provincial legislation, regulations, codes and guidelines). This project will provide important, relevant information and tools to Microboards that will assist Vela in developing and fostering increased competency of their Microboard members.



As well, Vela has received funding from the Vancouver Foundation towards a three year project that will assist Vela in providing the Microboard model to new and different sectors and establish partnerships within these sectors throughout B.C. Provincial organizations will be invited to make an application to work in partnership with Vela to develop Microboards for their constituents. This will assist Vela in reaching its goal to expand the Microboard model in B.C. and provide many more individuals and families access to the innovative and individualized supports they need and desire.

The Syd Vernon Foundation

The Syd Vernon Foundation Bursary, administered through the Vancouver Foundation, is provided in an amount up to \$3,500. It is available to graduate students and is presented in memory of Syd Vernon and his support of services for the disabled.

This bursary is made to Canadian students studying at Canadian universities. The recipient must show need for financial assistance and must have demonstrated, by their education, a commitment to working with people with mental and physical disabilities.

Eligibility Requirements:

- i) Graduate Bursary Assistance Application
- ii) Personal resume & covering letter
- iii) Outline of intended or current area of study
- iv) Transcript of grades
- v) Three letters of reference (faculty advisors, former employers, etc)

Application forms can be obtained by contacting:

The Syd Vernon Foundation

1963 West 36th Avenue
Vancouver, B.C., V6M 1K7

Telephone: (604) 689-5348

Email:

sydvernonfoundation@telus.net

Or, contact us here at Vela as we would be happy to forward an application to you.



2001 The Year of Volunteers

For more than ten years, Vela has acknowledged the importance of the contributions of volunteers. Friends and families volunteer their time assisting individuals and families actualize their dreams for their loved ones through a Microboard. More than 750 people volunteer as Microboard members, making Vela one of the most successful volunteer organizations in BC. As the year 2001 is the Year of Volunteers, Vela would like to salute and pay tribute to all the volunteers who help make Microboards a reality for so many.

As well, volunteers provide the Vela Microboard Association with vision and leadership through their role as Board members and committee members. Board members are involved in all facets of the planning and work of the organization. VelaVision is delighted to introduce Vela's volunteer webmaster and Vela's current Board of Directors.



Cathy Lafortune,
President
Castlegar, BC

Cathy Lafortune currently works as a medical transcriptionist and is known province wide as a powerful advocate for families. She has served on numerous boards and committees including her Community Health Board and the Premiere's Advisory Council for Persons with Disabilities. Her son Jeffrey, the eldest of four, lives at home and is supported by his microboard.



Cynthia Dillen,
Past President
Castlegar, BC

Cynthia Dillen has worked as an Early Childhood Educator and as a supervisor in an integrated

preschool with children with special needs. Cynthia was involved in the creation of a microboard for her brother, ensuring that Kevin's needs, desires, and dreams are realized. Recently Cynthia has taken a position as the worship pastor at the Garden Grove Church of God.



Jeff Moulins,
Secretary
Vancouver, BC

Jeff Moulins is a self advocate and writer who was involved in creating one of the first three microboards in BC. Through the involvement of developing his own microboard, he now speaks to individuals and groups about his experiences and what is needed to create a strong and meaningful microboard.



John Nyce,
Director
Vancouver, BC

John Nyce is a self advocate and a member of the Nisga'a Nation. John is currently a resident at the George Pearson Hospital. It is his dream and Vela's to assist him in leaving Pearson to live in his own home with the support of a microboard.



Dr. Peter Melhuish,
Vice President
Roberts Creek, BC

Dr. Peter Melhuish is a psychologist and a specialized health care consultant. Formally a senior manager in the provincial public service, with the Ministry of Health, he is currently developing a microboard for his teenage daughter Cicely.



Ric Tesan,
Director
Coquitlam, BC

Ric Tesan is a soccer coach and a Grade 7 teacher with the Burnaby School District. Over the past decade Ric has served as a director on several boards, including the Family Support Institute and the Planned Lifetime Advocacy Network. He is a strong parent advocate and has developed a microboard for his 22 year old daughter, Erin.



Sherry McDonald,
Treasurer
Fort St. John, BC

Sherry McDonald is an accountant with her own accounting service in Fort St. John and raises registered Paint Horses on her ranch with her husband, Bill. She is a strong advocate for her daughter, Holly, who lives in her own home with supports provided by her microboard.

Jennifer Cornish,
Director
Langley, BC

Jennifer Cornish recently spent a year in Haiti performing Missionary work: teaching English as a Second Language and providing physiotherapy to children in the missionary hospital. She has worked for several microboards and is presently supporting and living with a person with an microboard as a companion and roommate.

Watch future newsletters for information on our newest board members, Randy Wilson, and Gil Poitras!!!



Glyn Townson
Vela's Webmaster
Vancouver, B.C.

Glyn Townson, Vela's Webmaster, was born and raised in Vancouver and has spent most of his life on the West Coast. In the late 80's, Glyn's early involvement with computers was in designing spreadsheets and in data base management. With the advent of the internet, Glyn studied HTML and began designing and maintaining web sites. He began maintaining Vela's web site in 1998 and has presented workshops on the Internet and Communications at Vela Microboard conferences. Glyn's good nature, helpfulness and creative contributions are greatly appreciated by all at Vela.



The Who's Who at Vela

As we well know, it is the hard work and dedication of the staff at Vela that make the day to day operations of the Vela Microboard Association run smoothly. From your first call to the Vela office to the final stages of the development of Microboards, Vela's staff are there to guide and assist families every step of the way. Each member of the "team" comes to Vela with a wealth of skills and experience, as well as a deep conviction in individuals and families right to create a life filled with choices and opportunities for their loved ones. VelaVision is proud to introduce our current team of staff members.



Linda Perry,
Executive Director

Linda Perry, the 1999 recipient of the Community Living Institute's Leadership Award, has advocated and worked for people with disabilities for thirty years. It was Linda who developed Vela's first Microboards in 1990, and whose unparalleled commitment and leadership ever since has been pivotal and central to Vela's growth and development. Vela's many successes can be attributed to her ten years as our Executive Director. Family and friends play an integral role in Linda's life and she is the proud mother and grandmother to her daughter, Brandy, and granddaughter, Samantha. Linda is also a Sessional Instructor for the Human Service Worker Programs at Douglas and Channel Colleges.



Jeanette Holder,
Facilitator

Jeanette Holder is the mother of three children and developed one of the first Microboards on Vancouver Island for her daughter,

Jennifer, to ease the difficult transition to adulthood. Jeanette has supported the development of many subsequent Microboards on Vancouver Island since 1992, and brings a wealth of experience and practical knowledge to her position as a Vela facilitator. Jeanette also gives workshops on Transition Planning to Adulthood as a Regional Resource Parent for the Family Support Institute.



Lori Emanuels,
Facilitator

Lori Emanuels is a trained Licensed Practical Nurse, who has lived in the community of Cloverdale for 22 years with her husband and two sons. Lori has recently joined Vela's facilitating team, and previously worked for Vela's very first Microboard. She is a powerful advocate and spokeswoman for individuals with autism and their families. Lori, along with family and friends, supports her oldest son Chuck, with a Microboard.



Helen Stovell,
Office Manager

Helen Stovell, Vela's new Office Manager, brings a wealth of organizational and office experience to Vela. She also has the practical experience of being a mother of two teenage children. Helen is a strong advocate for families in her community and was instrumental in establishing one of the first Microboards for a child, her son Kevin. Helen is responsible for overseeing the management of the Vela office, and is often the first contact people will have with our organization.



Upcoming Events

Vela Microboard Association Annual General Meeting

Vela will hold its 2001 Annual General Meeting on June 9, 2001, 1:00 p.m. at the Sandman Hotel in Langley, B.C. Be sure to fill out your membership form, included in this newsletter, prior to the May 9, 2001 deadline.

Vela Microboard Association Conference 2001

Mark your calendars!!! Vela's Annual Microboard conference will be held October 12 - 14th 2001 at the Sheraton Guildford Hotel in Surrey, B.C. More information will follow.

Easter Seal Summer Camps

Register now! These residential summer camps are for children 6 to 18 years of age who have a mental and/or physical disability. They are free of charge. Camp Shawnigan is on Vancouver Island, Camp Squamish is outside Vancouver and Camp Winfield is in the Okanagan Valley. If you are interested register now! Call The Lions Society of BC, 250-386-0668 Toll Free: 1-888-868-2822 or email at camp@forthekidsbc.org

Cerebral Palsy Association and the Developmental Disability Association

Co-sponsor a support and information meeting for individuals with disabilities and family members of people with disabilities. Meetings are held at the Douglas Park Community Centre, 801 West 22nd Avenue, located just east of Oak Street, the 3rd Tuesday of the month at 7:00pm. For more information or to RSVP please call: Angela Swam CPA 604-205-9455 or Joan Wakeham DDA 604-273-9778. Please call in advance if you require on site child care.

Topics are as follows:

Tuesday April 17th, 2001, 7:00-9:00pm: Employment and Post Secondary Education Services and Materials.

Tuesday May 15th, 2001, 7:00-9:00pm: Augmentative Communication by Sunny Hill, Vancouver.

Tuesday June 19th, 2001, 7:00-9:00pm: Funding and Vocational Services.

Children's Variety Show

Wednesday April 18th, 2001 from 4:00 to 7:00pm at the John Oliver High School Auditorium, Corner of 41st & Fraser, Vancouver. You can obtain tickets from the BC Federation of Foster Parent Associations

Toronto Summer Institute

The Primrose Hotel is booked for July 6-13, 2001. Mark your calendars. Watch the Inclusion. Go to the website for more info, <http://www.inclusion.com>

Tash Conference

The 2001 Tash Conference will be held November 14-17th at the Marriott Anaheim, California. The TASH 2001 Conference Committee has identified interest in presentations that address the theme "Imaging the Future". For more information check the Tash website at www.tash.org

IF Project

The current direction of the Individualized Funding (IF) movement provincially, nationally and internationally was solidified at the July 2000 International Conference in Seattle through the development of the Declaration on Self-Determination and Individualized Funding. The conference and the Declaration helped renew the commitment to IF by identifying a set

of general principles which will shape how stakeholders, programs, groups, provinces and nations address and implement Individualized Funding.

The discussion regarding IF has brought together people with disabilities, family members, regional and provincial community organizations, service providers and professionals, creating the BC Citizens for Individualized Funding Coalition. In its vision statement, the Coalition committed to ensuring "people with disabilities are able to exercise their rights to freedom, equality and self-determination. When people require personal supports to enable their full participation in society, these supports must be provided in a way that upholds their rights. Funding for supports that is paid directly to the individual and based on individual need is the fundamental way to ensure the full rights of citizenship for people with disabilities."

For more information regarding the BC Citizens for Individualized Funding Coalition contact the IF Project of the BCCPD at (604) 875-0188

The following discussion groups and web sites provide further thinking on the subject of Self-Determination and Individualized Funding.

Discussion Groups and Websites Related to Individualized Funding

Discussion Groups

[Family Summit Distribution List: familysummit@home.com](mailto:familysummit@home.com)

(Discussion group for Families from British Columbia interested in I,.F. initiatives here in B.C.)

[Individualized Funding Discussion Group:](mailto:directfunding@home.com)

directfunding@home.com

(International discussion group on individualized funding)

Websites

Individualized Funding Website:

www.members.home.net/bsalisbury

(For anyone interested in international initiatives on IF)

International Self-Determination and Individualized Funding Conference Website:

www.members.home.net/directfunding

(Website for information on the International Conference on SD/IF to be held in Seattle, July, 2000)

Vela Microboard Website:

www.microboard.org

(Information on Vela supported Microboards with links to other IF sites)

PMG

The Provincial Monitoring Group (PMG) is a private company that monitors services for people with developmental disabilities in BC, through a contract with the Ministry for Children and Families (MCF).

PMG monitors the quality of a service using the Standards of Service established by MCF and the goal of each review is to ensure that each person receives a high quality of service that enables him or her to reach their individual goals.

As Microboards are unique, it is often asked how can a predetermined process reflect the unique nature of individual Microboards?

Flexibility is the key to the monitoring process. The PMG has worked closely with Vela, the Ministry of Children and Families (MCF), and Microboard members to develop a process for monitoring that clearly lays out the expectations for service, while also being flexible and responsive to the unique nature of each Microboard.

In every contract with MCF, there is a clause that says funded services must take part in an external monitoring process. The PMG has been contracted with the MCF to conduct the monitoring. It is a way for all parties to ensure that quality services are being delivered to the people using the services, as well as ensuring that monitoring is conducted in an objective, impartial manner.

PMG only hires monitors with direct experience working with people with developmental disabilities. Several of PMG staff members currently sit on Microboards or have had involvement with Microboards in some capacity. Some staff have family members receiving services through a Microboard. These staff members are training other staff members about the unique nature of services provided through Microboards.

For more information on monitoring, contact PMG at:

301- 2902 West Broadway
Vancouver, BC, V6K 2G8
Tel: (604) 733-1109
Fax: (604) 733-5058
pmg@telus.net
www.monitoringgroup.com

214- 1175 Cook Street
Victoria, BC, V8V 4A1
Tel: (250) 385-6482
Fax: (250) 385-6460
pmgvictoria@coastnet.com
www.monitoringgroup.com

Disabled Are Not Dogs

By Tom Koch,

Even severely handicapped children have a right to live life to its potential. Family members don't have the right to "put down" people.

Many Canadians believe Robert Latimer's 10-year sentence for the murder of his daughter, Tracy, was too harsh, and that "mercy killing" is an idea whose time is now. In British Columbia, MP Sven Robinson and *Vancouver Sun* columnist Stan Persky have taken this position.

Others insist a "mercy killing" law, or a royal pardon for Latimer, would endorse non-care for the fragile. Working through the Supreme Court's judgment, they're probably right.

Latimer's supporters justify Tracy's murder because she had untreatable pain. This isn't true, however. "There was evidence that Tracy could have been fed with a feeding tube into her stomach, an option that would have improved her nutrition and health," the justices wrote. This, they continued, "might also have allowed for more effective pain medication to be administered, but the accused and his wife [Laura] rejected this option."

"Had the Latimers not rejected this option of relying on a feeding tube," in short, the pain that drove Latimer to murder might have been managed.

Similarly, doctors said surgery removing Tracy's "upper thigh bone" would relieve the physical pain resulting from her hip dislocation, a complication resulting from her disease. But Latimer saw this as "mutilation" and killed his daughter instead.

A pardon for Latimer would say death is better than treatments like feeding



and amputation, even when they save lives, relieve pain, and improve health.

In the same vein, two years before Tracy's murder, the *Journal of the American Medical Association* reported on a new procedure to relieve the "spasticity" of patients like Tracy. It involved using an "intrathecal pump" to deliver controlled doses of medication directly into the spinal fluid. We know too, it was in use in Vancouver in 1993.

We don't know if anyone suggested this approach to the Latimer case - or if Robert Latimer would have accepted it - because it is easier to talk about mercy, and mercy killing, than it is to deal with the messy details of patient care. Finally, the months before Tracy was killed her parents decided not to place her in a group home where she could have received the care she needed. Provinces fund such institutions not only for patients, but for families who can't cope. Pardoning Latimer says, "Better to be gassed than to enter a skilled care facility." Tell that to Granny when she thinks about a retirement home.

But the Senate select committee on euthanasia advocated a lesser charge than murder in difficult cases, Latimer supporters agree.

They forget the committee also said that was to be considered only after first-rate palliative (pain management) treatment and care have been exhausted. They weren't here. Latimer rejected them.

Those who seek mercy for Latimer and minimal penalties for others like him sometimes argue: "Hey, we put down our beloved pets. Why not our loved ones as well?"

The answer is Canadians value their relatives and neighbours more than their pets. We therefore protect our citizens more carefully than the lives of cats, dogs and parakeets. One reason we

have a national health care system is to ensure everyone gets the treatment they need to live the best life they can.

Still, some say Tracy wasn't worth saving, Persky, for example, argues she was "without any prospect of a meaningful future." She was physically restricted and had the mental level of a four-year old. This is supposed to make her murder okay.

To say Tracy Latimer's murder wasn't important because her life was meaningless is to say the lives of the different are no lives at all. Unless one believes everyone who is developmentally and physically challenged has a meaningless future, who is to say her future was without merit? Can you draw the line that will say these lives are meaningful and those are not? I can't.

Finally, some argue Latimer shouldn't be treated like a common murderer because his motives were good. Since he's unlikely to kill again, what purpose is served by his incarceration?

The answer is simple. "Mercy" for Bob Latimer would give other relatives permission to kill their dependents without undue concern for the consequences. Arguing Latimer's sentence is "cruel and unusual" would say there is indeed little difference between putting down the fragile child (or parent, or spouse) and the family pet.

Latimer's 10-year sentence says parents, spouses and siblings don't have life-and-death powers over dependent persons. Offer Latimer "mercy" and you withdraw it from the fragile, whose lives may forfeit as a result.

To pardon him would be to say anyone can put down a son, daughter, or spouse just as you would arthritic, half-blind old Fido.

Tom Koch is an author and lecturer who writes extensively on medical ethics. Recent books include *Age Speaks for Itself* and *The Limits of Principle*.

Reprinted with the courtesy of Tom Koch from the Vancouver Sun, February 7, 2001.

Ralph White Interview



On January 18, 2001 in an unanimous decision, the Supreme Court of Canada turned down an appeal of Robert Latimer's murder conviction. Seven years ago, Latimer gassed to death his daughter Tracey, claiming he wished to spare her a life of pain. The Supreme Court called Latimer's actions "a gross error in judgement" concluding that the minimum sentence for murder which is ten years, "is not grossly disproportionate in this case."

Disability groups throughout the country heralded the ruling as a victory for all persons with disabilities, saying it recognizes every citizen as equal and that it puts value on the lives of people with disabilities.

On the same day Ralph White of Victoria, gave a wonderful interview on Chek TV providing an uplifting and radically different perspective on the life of his daughter Desa, who faces multiple challenges. In 1974, not long after the birth of their first child, Ralph and Virginia White, were told their

daughter Desa would have severe disabilities. After having three children in 39 months, it was suggested to Ralph and Virginia that they use the Queen Alexandra Hospital in Victoria for respite. Two weeks turned into sixteen years as they realized that the Queen Alexandra was the best available option in providing their daughter with the round the clock care she needed. The family shared their time between the hospital and their home, visiting Desa every weekend. During this time, the family continued to pursue ways in which they could bring Desa home, knowing that they could not care for her alone.

More than seven years ago the White's were able to bring their daughter home with staffing supports through the help of a Vela Microboard. This was the very first Microboard that Vela had developed for a person leaving an institution. Since moving back home, Desa's life and health has improved significantly, alleviating many of the problems that bothered her while in the hospital, including chronic sores and seizures.

During the interview Ralph explained what a Microboard is and what a big difference he has seen in his daughter since her Microboard was developed. He spoke of the many things that have changed for Desa and how her ability to communicate has increased as a result. Desa now has caregivers to support her and it is estimated that the cost of her care at home is approximately 25% of the cost of living in an institution. Ralph and Virginia revamped both their life and home to get their daughter home and even designed specialized equipment to meet Desa's unique and complex needs. Virginia designed a set of pedals to attach to Desa's wheelchair to allow her to get exercise and a revolving wheel for the track system in her bathroom

allowing her to move around more easily. For the White's, having Desa home has made a huge difference for their family, filling them with much joy.

The interviewer asked Ralph, what kinds of contributions that his daughter and people with disabilities can make. Ralph answered by describing his daughter as giving great warmth and love to others and how she is bright and happy with no hidden agenda. He spoke of the profound effect she has had on people and of her humour and courage. He also said that many people are unaware of how a person with disabilities can touch the lives of others, and that if more people were as sincere, open and honest, many of the worlds problems would be smaller.

When a women called into the program, she spoke of how people had difficulty getting past the wheelchair her sister uses and how they often make incorrect assumptions. Ralph described how they welcome people to ask questions and encourage them to come and meet Desa, to take her hand and to say hello. The White's have helped Desa to not feel badly towards those people who don't have skills or experience with people with disabilities, and how they themselves can help people in their understanding.

The inspirational interview involved an interview in the Chek TV studio with Ralph as well as interviews in the White's home with Ralph, Virginia and Desa. It is an incredible story of the perseverance and dedication of families against the backdrop of one of the scariest moments in Canadian history, for people with disabilities.

Autism Treatments

On Wednesday, February 7, 2001, Justice Marion Allen ruled that the B.C. government must pay for intensive, early therapy for children with autism. This decision is an extension to a

previous ruling that Justice Allen made last year that found the government's refusal to provide early treatment for autism was indeed a violation of the children's Charter rights guaranteeing equal treatment. The province of B.C. is appealing that decision.

Justice Allen ordered the government to provide treatment and stated, "The government is obliged to provide effective treatment to accommodate the disadvantaged position of autistic children." She added, "It cannot deny or delay implementation of early (treatment) on the basis of cost."

The court case was launched by four families of autistic children who wanted compensation from the court to pay for the costs of Lovas therapy, an intense, early intervention treatment using one-to-one treatment for children six years and under. The parents in the case have spent hundreds of thousands of dollars on the therapy that costs up to \$60,000 per year.

In a symbolic gesture, Justice Marion Allen awarded each of the four families \$20,000 saying, "A symbolic award provides partial, albeit minimal, compensation to the petitioners and acknowledges the intransigence of government in responding to the long-standing requests and demands for autistic treatment."

The judge recognized that Lovas therapy is effective, but added it was not up to judges to create public policy. "The judiciary cannot dictate what treatment programs should or should not be implemented, nor can it dictate how limited financial resources should be allocated."

Just prior to Justice Allen's ruling, the provincial government the new Provincial Centre for Autism and Related Disorders for autistic children between the ages of two and six. This



program does not involve a component for Lovas treatment and is seen by parents as too little, too late. It is being criticized as being too narrow and restrictive and without proof of effectiveness.

Parents from the group, Families for Early Autism Treatment are skeptical that the government will follow through on its obligations as ruled by Justice Allen. The group has lobbied for over five years and have felt the government has not been working in good faith.

But Finance Minister Paul Ramsey has assured that the government "has no intent to do anything other than comply with this ruling."

Still, in order to provide young autistic children with the most effective treatment, parents will most likely have to pay themselves.

Vela's Annual General Meeting

Vela Microboard Association will hold it's 2001 Annual General Meeting on June 9, 2001, 1:00 pm, at the Sandman Hotel in Langley, B.C. All members who wish to attend must be in good standing. Our membership fee structure is as follows:

Individual (*sliding fee available if necessary for self-advocates and/or family members).....\$ 25.00

Non profit Societies, Businesses & Organizations.....\$ 100.00

In order that you may be considered to be a member in good standing membership fees must be received one month prior to our AGM. Each membership allows one vote.

Members wishing to put forth a nomination for the Board or Directors must do so with the permission of the nominee. Each nomination is required to be accompanied with a brief bio of the nominee. It should be noted that all nominees **MUST** be members in good standing. All nominations **MUST** be received at the office of Vela Microboard Association by May 9, 2001, one month prior to the Annual General Meeting.

If you wish to attend the VELA AGM, please RSVP to our office by May 23, 2001.

Please contact Helen Stovell at the Vela office for more information regarding the Vela AGM.

Vela Microboard Association of BC
MEMBERSHIP FORM

Name/Organization: _____

Address: _____

City: _____ Prov: _____ Postal Code: _____

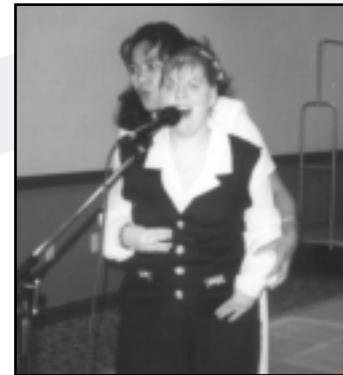
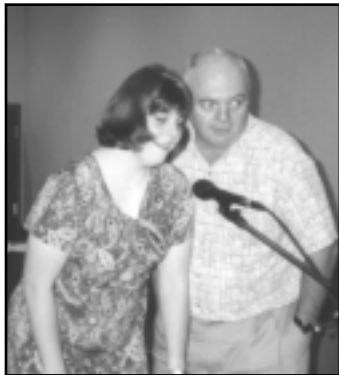
Telephone: _____ Fax: _____

Yes, I wish to become a member of Vela Microboard Association.

Amount Enclosed: \$ _____ Individual

Amount Enclosed: \$ _____ Non-Profit Society,
Business,
Organization

Mail to: Vela Microboard Association of BC
5686 - 176th St., Surrey, BC, V3S 4C6
Or Fax to: (604) 575-2589



VELA MICROBOARD ASSOCIATION OF B.C.
 A small, dedicated organization doing important work

Vela Microboard Association of BC is a small non-profit organization that does the big job and the important work of developing microboards for individuals and families throughout British Columbia. Vela relies on donations and the generosity of its supporters and sponsors to continue its work.

How you can become a Vela supporter

You can help support Vela and its work by making a donation. All Vela supporters will receive copies of the *Vela Vision* newsletter and information mailouts.

You may also wish to leave a legacy for the future through a planned gift or bequest in your will or through a gift of life insurance.

Thank you for supporting Vela Microboard Association of BC to continue its work developing innovative and individualized supports and options for people with disabilities.

Vela Microboard Association of BC
DONATION FORM

Name/Organization: _____

Address: _____

City: _____ Prov: _____ Postal Code: _____

Telephone: _____ Fax: _____

All Donations of \$10.00 or more will receive a tax receipt

Yes, I wish to become a Vela supporter.

I wish to make a donation in the amount of _____.

I wish to leave a legacy and would like information on how to make a bequest.

WE THANK YOU FOR YOUR SUPPORT!!

Mail to: Vela Microboard Association of BC
 5686 - 176th St., Surrey, BC, V3S 4C6
 Or Fax to: (604) 575-2589



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