



L'Arche Canada offers this "thought sheet" as a contribution to the public conversation about values and the shaping of the social ethos in which we live. Our perspective comes from two broad sources: (1) from forty years of living together in community as a diverse group of people, differently abled and from various cultural, ethnic and religious backgrounds; and (2) from contemporary thinkers who are open, fresh and responsive to the human spirit and are reflecting deeply on the individual and society today.

The vision and confidence to create a healthy Canadian society lies in the nexus where humanistic thinking and spirituality cross-fertilize. Indeed, today the best spiritual thinking engages contemporary culture with a view to the good of human society and the best humanistic thinking integrates spiritual values. We believe it is possible to live consciously in the gap between an ideal society and everyday reality and to make choices that contribute to the closing of that gap. It is a hopeful view, based on human and spiritual values embodied in daily life.

A Human Future

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Walker Brown: Pool of Hope; Collective Work of Art; Teacher An Interview with Ian Brown



Ian Brown is a feature writer for the *Globe and Mail* and anchor of TVO's *Human Edge* and *The View from Here*, Canada's pre-eminent television documentary series. For ten years he was host of CBC Radio's *Talking Books*. His reporting and editing have won more than a dozen national magazine and newspaper awards. He is the editor of the anthology *What I Meant to Say: The Private Lives of Men*, and author of the books *Freewheeling* and *Man Overboard*, and most recently, *The Boy in the Moon: A Father's Search for his Disabled Son*.

This fall, Random House published Ian Brown's very beautiful, and to some, controversial, book *The Boy in the Moon*, about his journey with his son Walker, who is profoundly disabled by cardiofaciocutaneous syndrome (CFC), a rare genetic disorder.

A Human Future, is a free e-quarterly. Subscribe at www.larche.ca. We do not share our subscriber list. Beth Porter, ed.

Beth Porter: Has Walker made you a better writer?

Ian Brown: Definitely. He's made me more concrete. Hemingway said there're two problems in writing. One is technical – how do you make the reader feel things with words on a page. But the other harder part is to figure out what you actually know to be true, as opposed to what is supposed to be true, or others want to be true, or you hope will be true so that you look good. Walker made me realize that you have to go back to what actually happens. If you describe that, it will tell you what you feel.

At first I was very nervous about the book. I felt that people would not understand these stories. And I was concerned that people would think this is just a book about 128 kids with CFC, or about disability. Whereas I always thought of it as about the struggle of those who are disabled to be seen as contributing individuals, no matter how subtle or small their contribution might seem. It's something we don't want to see. And it's the struggle of any oppressed class – women,

"Walker's a radical sort of person... he's taught me to look for the unexpected."



John Keats’ “Negative Capability”



B.R. Hayden

This phrase may confuse people... The concept of Negative Capability is the ability to contemplate the world without the desire to try and reconcile contradictory aspects or fit it into closed and rational systems.

Keats longed to find beauty in what was often an ugly and terrible world. He was an admirer of Shakespeare. In a letter to his brothers, Keats describes [Shakespeare’s] genius as “Negative Capability ... when a man is capable of being in uncertainties, mysteries, doubts, without any irritable reaching after fact or reason.” ... Keats’ creative concept seems positive and full of potential...

[In a certain sense] Negative Capability is a sublime expression of extreme empathy. And empathy is the capacity for participating in, experiencing and understanding another’s feelings or ideas. It’s a creative tool to help us understand each other, understand different point of views or different cultures so that we might be able to express them.

Extracted from “Keats’ Kingdom: The Best Keats Resource on the Web.” [Click here for link to site.](#)

black people, gay people, the aged. Even more, it’s the struggle of the individual and specific against generalities which tell you nothing. Every human being wonders...fears that their voice will not be heard.

Some people dislike the way you describe Walker.

I think being candid is important. I include a poem by Wendell Berry in which he says that candour is the only power you have against the shame that the rest of the world would like to visit upon you – a shame that is not unfamiliar to anybody who has anything to do with disability. You look at Walker and wonder how much of him is in there, what is he taking in. This is true with any person with a severe intellectual handicap. If you don’t ask this question, you have to wonder why you don’t. The challenge, of course, is to not be misled by appearances and to engage at another level – at which point you realize how much such a person *is* there – often far more than we “normals” are really there.

How do you see Walker’s contribution?

Walker has made me realize that there’s more than one way of measuring the value of a human life. He’s a radical sort of person for me, because he shakes up my view of success and what is important. I’m not saying Walker’s way of being is superior, but it is an unexpected way. He’s taught me to measure things in that light – to look for the unexpected. There can be an indescribable grace in this. Sometimes Walker, perhaps rolling a baggie full of pop can tabs in his hands, makes me think of John Keats’ idea of Negative Capability.

The first time I thought about Walker’s possible contribution was when he was two and a half and had started to hit himself daily. A developmental pediatrician told us Walker was going to be moderately and probably severely retarded. I said that in the past summer we had taken Walker to a cottage on Georgian Bay, and that in the evening stillness with the sunset reflecting on the water, Walker would change. He’d become more alert, calmer, sit up straighter, not trying to hit himself. I asked, Will I ever be able to explain to Walker how much that

“Glass Pieces”



Bruce Zinger

Artists of the National Ballet of Canada performing Jerome Robbins’ “Glass Pieces.”

Fashioning his own aesthetic that was equal parts classicism and indigenous American vernacular, Jerome Robbins staked out a unique position in modern dance, exemplified beautifully in his breathtaking 1983 work Glass Pieces, set to the haunting minimalist ruminations of Philip Glass.

*Glass Pieces uses 42 dancers performing on a stage with a backdrop of grid lines resembling graph paper. Described by critics as Mr. Robbins’ urban work, Glass Pieces does not employ the emotional imagery often seen in his work. The dancers perform with emotional restraint even during the third movement, where the tribal rhythms of Mr. Glass’ opera score allow the dancers to build to a regulated, almost mechanical frenzy on stage.**

*Of this third movement, New York Times reviewer Alastair Macaulay writes, “Again Robbins builds startling effects out of slight changes of vocabulary (an extended arm, or the break from pacing to running). The introduction of new characters becomes momentous, modestly but wonderfully so....” ***

*Extracted from the National Ballet of Canada credit page for “Glass Pieces,” November, 2009. (Watch a short video: [click here.](#)) ***New York Times*, June 7, 2009.



part of the world means to me? Or that it matters to me that what is important to me might be important to him also? And the doctor said, No, not rationally probably, but it sounds as if he already understands this. As the Buddhists would say, the trick is to get your mind out of the way in order to just be. Walker is capable of just being who he is without apology, and in this sense he is probably ahead of us all.

You write of Walker’s attention to the detail of a Christmas ornament. Then you say he can be “a lens through which to see the world more sharply, one of the pools where hope resides.”

To grasp the value Walker can bring you have to stop what you think you should be doing – cooking, being the good host – and pay attention to the moment, however unconventional.

I met an experimental geneticist, Denis Noble, who explained that if you look for the mind in the brain all you’ll find is a bunch of chemicals. You can’t find a mind. Intentionality, hopefulness, generosity, revenge – none of these exist in the brain; they only exist in the neural pathways we create between one another, as a kind of collectivity. So, Walker may not have much of a mind if you measure it as a bunch of neural-chemical reactions that misfire, but he has a big mind if you look at the ideas and gestures and commonality that he inspires between a vast group of people who know him. He can be seen as a collective work of art that is there for all of us to respond to.

With Walker’s sister, Hayley, I saw the beautifully choreographed Jerome Robbins ballet “Glass Pieces.” It depicts life in a city where everyone does the same thing everyday, but every so often someone separates out and then goes back. It’s a hopeful vision, and it made me cry – with gratitude, I suppose – much as Walker sometimes makes me cry. I realized that there is a collective aspect to hope. It takes someone to venture and someone to respond.

You visited Jean Vanier and L’Arche in France. How was that?

I felt enthralled because I think it’s a very viable model; but

defeated because it's so rare. The disconnect between the incredible, transformative experience of hanging out there for three days and then finding how afraid people here are to engage with the subject, that I find disheartening.

As a parent you get pretty lonely, and alone I get angry, almost despairing, when I realize how completely ignorant most of society is of what it's truly like to raise a severely disabled child. I'm not blaming anyone, but the simplistic idea of ladders of success to climb and so forth just doesn't work. Walker doesn't just like to be with us; he likes to be with people like himself where he doesn't have to compete. Our society's managerial, technocratic approach, its power-points and obtainable objectives, is only geared towards "solving the problem," making people with disabilities more like us. We are afraid of weakness. It reminds us of our own potential disability and death.

How could your insights influence public policy?

If we were smart about public policy, we'd ask, What would be an arrangement where people like Walker would gain but we also would gain? Then we don't have to be altruistic, we can be selfish. What is needed is not to cure or fix their spirits, but to create communities that help their spirits thrive.



The L'Arche movement was founded by Jean Vanier, in France in 1964. Today there are 136 communities of L'Arche on six continents, 29 in Canada. In L'Arche, people with developmental disabilities and those who come to assist them share life together.

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FOR YOUR INTEREST

Cardiofaciocutaneous (CFC) syndrome

CFC syndrome is a rare genetic condition that typically affects the heart (cardio), facial features (facio) and skin (cutaneous). It is seen with equal frequency in males and females and across all ethnic groups. Children with CFC syndrome may have certain features that suggest the diagnosis, such as relatively large head size, down-slanting eyes, sparse eyebrows, curly hair, areas of thickened or scaly skin, and small stature. Most will also have a heart defect. While there is a wide spectrum of severity in CFC syndrome, most individuals will have some degree of learning difficulty and developmental delay.

The CFC International website, a family support network. [Click.](#)

Resources (click on websites)

- "The Boy in the Moon" – Five part series in the *Globe and Mail* with pictures and video clips: www.theglobeandmail.com
- *The Boy in the Moon* on short list for British Columbia National Award for Canadian Non-Fiction: www.theglobeandmail.com
- Ian Brown writing about e-books: www.theglobeandmail.com
- Denis Noble, pioneering Oxford systems biologist speaking on the message of his book, *The Music of Life*, a book which is critical of genetic reductionism and genetic determinism. www.musicoflife.johnsjung.com
- "Do Not Be Ashamed," a poem by Wendell Berry in *The Selected Poems of Wendell Berry*, Counterpoint, 1999.
- TVO's The Human Edge: www.tvo.org
- The View from Here: www.tvo.org
- Earlier books by Ian Brown:
 - *What I Meant to Say: The Private Lives of Men*, 2006, a collection of 29 essays by prominent Canadian writers. Edited by Ian Brown.
 - *Man Overboard: True Adventures with North American Men*. (1994).
 - *Freewheeling* (1989), about the Billes family, owners of Canadian Tire.

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