

The Wind Beneath Their Wings

Lifting Expectations of Young Blind People in a Visual World

by

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CNZM, OBE, B.PHYSIOTHERAPY, DIP. MANIP. THERAPY, CERT. REHABILITATION

Abstract

Drawing on personal experience, this article explores some factors that have shaped my life from 'blind kid' to having a great family and a rewarding career and heading the major organisation providing blindness services in New Zealand. Making it as a blind person in a visual world is no 'cakewalk'.

While the question posed by the title of this article won't be answered (as the solutions are as varied as individuals) some themes are offered for reflection.

As professionals you are in an excellent position to gather the elements required to live effectively as a blind person in today's world; and to advocate for those elements to be actioned. Such elements form the basis of your professional practice. They deserve to be researched, codified and disseminated.

The general themes I'll canvas include:

- * The significance of parents and role models
- * Learning to move with confidence and ease
- * Digging deep inside 'the self' in order to sell your message with authenticity
- * Helping others to build resilience, self efficacy and adaptability within a personal context
- * Recognising that ultimately people rehabilitate themselves; sometimes with the help of professionals.

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Foreword

From the start may I make a few things clear:

- First, the views expressed here are my own and based on personal experience.
- Second, I don't have the answers to the question posed by the title. The title is a framework for your own reflection.
- Third, I am an imposter! I don't know how to use a long cane - I got going before Dr Richard Hoover; and I don't know much about the science of orientation and mobility. However, I do know that blind people will benefit from you sharing ideas and from thinking critically about your daily practice using the disciplines of science.

There are parallels between teaching mobility skills and physiotherapy. Both constitute rehabilitation. By rehabilitation, I mean gaining functional independence and well-being. Some of you are involved in habilitation as well. The objective is the same although the approach is different.

We do more than impart skills. We are engaged in a deeply human experience. On the one hand, we are about having a background in science - what works best given current evidence - and thinking critically about outcomes. On the other hand, there is a need for empathy and an appreciation of the place in society of vulnerable people.

We are about banishing boundaries and developing potentials. We are about learning to live life anew and being okay with difference. We are about helping people adapt to circumstances in a world where there is not a lot of accommodation to blindness; where there is not much awareness of vision loss; and where expectations of the public are either impossibly high - super-blind; or zilch - "sit down and we'll look after you"! So the challenge for us is to offer blind students realistic expectations and to expand their possibilities. As Darwin said, it is not the strongest and fittest that survive but those who adapt to change.

Daily life for blind people involves finding work-arounds to micro-challenges. Micro-challenges are of both a physical and emotional nature such as reading a document,

finding a doorway, politely dealing with comments like "it's over there" or "be careful"!

In this article, I want to emphasise the social and emotional maturity that goes with surviving as a blind person in the visual jungle. In using the word 'blind' I mean blind *and* low vision. Partially sighted people face ambiguities, uncertainties and anxieties in dealing with life that are less well understood than obvious blindness.

The two main themes I will explore are:

- The place of parents, play and peer role models as the springboard for moving with confidence and ease, and
- Lifting our expectations relating to our own social and emotional development. Therefore, building personal resilience, self efficacy and adaptability to pass on to others.

Theme One: The place of parents, play and role models

In telling the story of my early years I'm not looking back to the future. I want to improve the current system. Over the last generation blind people have gained much in educational terms, but have we lost something as well?

I was born at Hastings in 1940 of poor working-class parents. Infantile glaucoma compromised my sight and by age five it was clear I would become blind. The family moved to Auckland so I could go to school at the Blind Institute and live at home during weekends.

The teachers at the Institute were dedicated and expected nothing but the best. I learned Braille, touch typing and the confidence to move around freely. Agility and mobility were taken for granted. Tricks of the trade were picked up from older pupils who were role models. We didn't feel special. We found security in being normal.

We invented our own games, some of them very physical and we grew according to ability. Riding bikes, kicking and catching balls and climbing trees were the norm. As kids we learned to skip rope by listening, judge high-jumps, and to dive from springboards at the public pool. Nothing new in 'echo-location'.

Crafts that involved finger dexterity, sewing, weaving, and beadwork were commonplace. Older boys taught me to make crystal sets and imparted the Morse Code. Competitive sport and music - learning an instrument - were big. Moving around freely and playing games was a matter of survival and a great teacher.

I suggest to you that free uninhibited play from the very beginning - from infancy - is the developmental basis of good O&M skills. Opportunities for such play may be limited by the way we do things currently.

Being 'mainstreamed' in a secondary school and university was a 'wake-up' call. Braille texts were scarce. We were reliant on college students reading to us. Notes were dictated by fellow students. It was a question of coping as a blind person in a visual world - seat of the pants stuff managed with the help of mates. There was no sport or girls.

Winning an RNZFB scholarship to study Physiotherapy in London was a joy beyond belief because all the texts and other learning aids were accessible.

On return to New Zealand I was reminded how lucky I had been to have gained a 'ticket' to a career, a wife and a guide dog. So I joined the Foundation's Board in 1972 and became the first blind person to chair the Board in 1980. I then moved on to local politics, a role I still do to this day.

Key Lessons

- My parents knew nothing about blindness, were not engaged in my education so let me get on with it without angst. Their approach? A mix of 'matter-of-factness', caring support and expectations to achieve. "Others have done well, so can you".
- My peers were role models. They taught me heaps - still do. We were a cross section of society. Blindness knows no cultural bounds.
- It is not what happens to us that counts, but what we make of it that matters.

Raising our game: we can do better by our blind kids!

If we ever hope to influence the lives of others, we must understand them in terms of their own needs and aspirations. To do this successfully we have to understand our own needs and perspectives and remain open to ongoing personal growth. It is hard to influence the behaviour of people, including parents, if they are not understood on their own terms. You face the challenges of enabling blind people with various losses to focus on undreamed horizons. Your job is to unwrap new futures by helping people discover other ways of knowing, other ways of doing and other ways of being.

Here's the rub! What we all know from personal experience is that the best learning takes place when relationships are positive and affirming; when mentors are realistic, kind, yet candid. Working with young people is a journey of discovery that is not always in the comfort zone of practitioners such as yourselves who must operate within ethical boundaries.

The dilemma is, you know from your own experience that many of life's lessons were learned outside the classroom; outside school. Many of those experiences, some enriching, some disasters, were modulated by peers who knew their way around! Often older buddies. Many of your learning's were picked up incidentally by

knocking about with other kids. Blind people don't learn from watching and often don't operate on the same broad social canvas as their sighted peers.

It is a tough call for blind students. They have to master the regular curriculum, do double time acquiring adaptive learning skills including ever-changing technology and mobility, then search out the social skills for living, learning, earning, and loving as blind people in an image laden world.

I think there is a huge gap in 'mainstream' education for blind students because of a risk adverse culture and the lack of shared experience with peers in a non-special environment. If you want kids and their families to learn, let them loose on one another. The solution: more camps and Whanganui river trips! Yes! More cash up front but much cheaper than adult dependency.

Today's 'mainstream' formal learning is necessarily risk averse. I suggest the expectations of blind kids would take a giant leap forward if there was more early parent involvement in setting goals; and if there was more exposure to role models and better support for out-of-school activities. The centre of gravity needs to move more toward the social and emotional development of the blind child and adolescent. More pupil-centred. The concept of 'mainstreaming' is a good one but is hung up with adult concerns. That said, there are some fantastically gifted blind achievers out there but let's keep raising the bar for the average student.

Theme Two: Lifting our Own Expectations

The challenges you and I face in our daily work are puzzling and often messy. People can't be shoehorned into service boxes. Compared with the rigors of science, our professional issues are mixed up human situations. They are situations not entirely resolvable by rational and technical approaches. Solutions to problems are often financial, environmental, attitudinal and political in nature.

The challenges we face may not be related to the external world as much as with the client's internal world; part of coming to terms with self. Better to know the client with the vision loss than what vision loss the client has. Our professionalism lies with appreciating individual needs, applying the best evidence, showing honest concern and compassion, giving people time, helping people to gain the best outcomes for themselves, and unleashing potential.

You and I need intuition as well as rationality to make any kind of difference. We are not about curing, fixing or changing people to conform to society's norms. We are about dealing with the daily realities of living with blindness. Delivering power into the hands of clients so they can control their own well-being; so they have the tools to take charge of their own lives. Our goal is not to make life problem-free but to give

ordinary life depth and value. To enable people to give expression to who they really are.

All this takes humility, reflection, discipline, teamwork and continual self growth on our part. As neuro-scientist Jill Bolte-Taylor says, "many of us think of ourselves as thinking creatures that feel; biologically we are feeling creatures that think".

I agree with the view that rehabilitationists like you and me have a moral obligation to integrate traditional scientific thinking with a deep understanding of the philosophy, knowledge and practice of human caring. Professional development should value wisdom, spirituality and ethics, as well as intellectual and technical skills. Such concepts have been in the literature for more than two decades and are reinforced by modern neuro-science.

Summary

Putting wind beneath the wings and lifting expectations of young blind people in a visual world is about our professional growth - including our social and emotional fitness to build positive attitudes and the hopes and dreams in others. Living with blindness in an increasingly image bound world whether young or not, calls for intangible qualities such as emotional resilience, social grace, self efficacy and motivation; patience and persistence, self control (more than self esteem), a sense of humour and humility, the ability to handle frustration and failure, the courage to take risks, curiosity, not being disabled in spirit, making the most of what is, and knowing when to adjust oneself to circumstances or, circumstances to oneself.

Acknowledging the social and emotional determinants of well-being as part of what you do will pay dividends. So will the accumulation of hard evidence that validates what you do in terms of quality of life, cost-benefit ratios and the realisation of the human potential that is in your hands.

How people with disabilities are treated is an index of the society in which we live.

"With all its sham, drudgery and broken dreams, it is still a beautiful world" (Max Ehrmann 1872 - 1945) made up of wonderful people who believe in a fair go.

The only difference between a happy person and a broken soul is never the problem, it is our attitude towards the problem that makes us what we are.

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