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A friend for life

By Kevin Kinghorn
Staff writer

"Having a disability really becomes an insignificant difference when you realize that we're all in a leaky row boat together."—Al Edmanski, co-founder of Planned Lifetime Advocacy Network

A cold wind spins bits of straw in miniature whirlwinds as a bank of bruise-coloured clouds creeps over the tree line. The threatening weather doesn't bother Gordon Walker, who makes a distinct jingling sound as he walks from stable to paddock to show off the horses in his charge. He pulls a small spice jar filled with loonies out of his jeans pocket and gives it a loud shake.

"Money for the bus," he says with a broad grin. He's been making the 10-minute bus ride from his Kerrisdale apartment to his job at Maynard Stables in Southlands by foot since the transit strike began, but still carries the coins with him in case the buses start running again.

Walker knows the name and temperament of every one of the more than 20 horses lodged at Maynard's. He points to one horse, the "amazing" Impy, who's currently in a heated head duel with a horse in the neighbouring paddock. Impy learned how to work a latch last year and has sneaked from his muddy plot four times to graze on the tall grass behind the barn.

Walker lets out a piercing cackle at the memory of Impy's last escape.

"All the other horses were standing around wondering what was

to his family and just about everyone else 12 years ago.

Walker is a living advertisement for the Planned Lifetime Advocacy Network, a non-profit society that helps people with disabilities live meaningful, independent lives in the community. PLAN connects people like Walker with a network of friends who not only assist on a practical level by doing anything from giving them a ride to a doctor's appointment to taking them out for a beer, but more importantly, offer their friendship—something PLAN says is much more valuable.

Like many people with intellectual disabilities, Walker spent the majority of his life at home tethered to his parents. He had little connection to anyone or anything outside a restricted family circle. He sometimes took advantage of the odd work program for people with similar disabilities—such as sweeping floors in a North Vancouver cement plant—and he enjoyed playing floor hockey in the Special Olympics, but mostly lived a withdrawn life at home.

That changed in 1988 when Walker's mother, Catherine, died. Suddenly his father, Chuck, a retired marine biologist, was faced with having to plan for Gordon's life after he too passed away. Initially he planned to sign his large Kerrisdale home over to a social service agency that would turn it into a group home where Gordon and others like him could live out their lives under full-time supervision. It wasn't an ideal situation, but it appeared the best option—until he stumbled upon Vickie Cammack of the Planned Lifetime Advocacy Network while trying to set up a trust fund for his son.

Cammack, director of member services for the Burnaby-based non-profit organization, explained that while financial security and professional services are great, what truly provides a good and meaningful quality of life is friendship.

"We believe that the biggest handicap for a person with a disability is their isolation and their loneliness," she said. "No matter how much money you have, if a child has no friends, they're going to be in trouble because friends are what give meaning to life."

Disabled people are surrounded by a revolving door of social workers paid to be with them, which Cammack insists is different from being surrounded by friends, no matter how caring the workers may be.

They tend to take care of all the disabled person's needs, which unwittingly robs them of independence, and by extension, of making a valuable contribution to society. The relationships are often short, tenuous and breed dependence on professional help rather than fostering autonomy.

What PLAN does is establish a network of a dozen or so people who commit to the welfare of a disabled individual for life. It's called a "circle of friends," and it's made a dramatic impact on the lives of more than 100 individuals with disabilities in the Lower Mainland, ranging from a biologist with severe multiple sclerosis to a 56-year-old man with autism. It's proven so successful that PLAN's model is being copied throughout North America and one of the founders was recently given the Civic Merit Award for his work—one of the highest honours the city bestows upon a citizen

Gordon Walker was one of the first members of PLAN. He was extraordinarily shy to begin with, but after his circle was set up almost 10 years ago, he began to come out of his shell. For the first time, Walker talked about his desire to move out of his childhood home and find a real job. With the help of one of his PLAN friends, he found steady work at Maynard's that he enjoys and now lives in his own apartment. He takes in a few Canucks game every year—he treats every member of his circle of friends to a game each season—and keeps a large cat named Reuben. In fact, he's so independent that his father Chuck moved to Vancouver Island years ago and now only visits Gordon on weekends.

Walker is a meticulous worker. Straw broom in hand, he methodically moves from one end of the stable's concrete floor to the other, not missing a single oat, blade of hay or clump of dirt. It's part of Walker's daily duties at Maynard's—a job he loves because of his affinity for horses. He says he even likes mucking out stalls and no longer notices the smell, though he could do without the horse hair, dog hair and every other kind of hair that attaches to his fleece vest.

As he shovels the fruits of his sweeping into a plastic wheelbarrow, a grey SUV pulls up and a woman with shoulder-length red hair wearing riding boots jumps out seconds before a rambunctious dog named Mika.

Walker trundles out of the barn and is immediately accosted by Mika, who shoves her nose between Gordon's knees. He vigorously scratches Mika's backside as the dog's entire body wags wildly.

"She's never going to leave you," warns 39-year-old Margot Vilvang, a Southlands riding instructor and mother of three. Gordon cackles his trademark laugh and continues scratching anyway.

Vilvang is a member of Walker's circle of friends. She keeps two of her six horses at Maynard's and met him five years ago when he first started at the stable. After hearing about PLAN and the circle, she decided to join.

"We just really get along," says Vilvang. "I have a lot of respect for him and what he does. I like the way he works with the animals.

He's a very caring, gentle, calm person."

While she sees him every day, Vilvang says she doesn't spend much time around Gordon, other than the occasional trail ride together, but is there if he needs a ride to the doctor or someone to talk to. "I don't find the commitment a huge responsibility at all," explains Vilvang. "He's got his routine and he's very self-sufficient." She knows Walker's situation may change in the future—he's been increasingly bothered by arthritis in his knees in the past few years— but she's prepared.

"It's really no different than being friends with him," she says. "I'll be there to help him in whatever way I can."

Part of what makes the commitment less of a strain on Vilvang is the fact that she's not alone. There are 11 other people in Walker's circle who also share her dedication to him. And besides, as she points out, it's not just a one-way street.

Walker looks after the two horses Vilvang keeps at the stable when she's away. "He's very reliable," she explains. "If I'm going away I ask him to look after them because he's so conscientious that way. Other people would forget to give them water or whatever but he's very responsible."

In fact, she says Walker is so caring and conscientious that he probably worries more about her than she does about him.

"Last month I had to have one of my horses put down, and I think it was hard for Gordon because he didn't know what to say to me," says Vilvang, tears beginning to well up in her eyes. "I think he avoided me for a bit but then he just walked up and gave me a big hug. He's always very concerned about me."

Ryvyr Tupper is a 38-year-old special education assistant at Moberly Walter Annex who acts as Walker's facilitator, arranging meetings between his circle and generally managing Walker's network. There's Tom who's in his 30s and studying to be a librarian, Nelson, a long-time friend of Walker's and his old neighbours Sue and Bill. Jeff is in his 30's and builds movie sets. He likes to take Gordon out for walks with his dog a couple of times a month. Another friend helps Gordon with his computer and others have him over for dinner with their families on holidays or whenever they think Gordon might like company.

"Once people meet Gordon they're just interested in him," says Tupper who affectionately calls him the "Wild Man" because of his hair. "He's just a really good friend who really cares for people and he has a great sense of humour. I kind of see him as a big bear with a really big heart."

Tupper, who lives in Horseshoe Bay, says Gordon has taken it upon himself to warn her about Lion's Gate bridge closures ever since repairs began. She often comes home to an answering machine with messages on it from Walker reminding her to take the Iron Workers' Memorial Second Narrows Bridge instead.

"A lot of people are just fearful of people with disabilities," Tupper explains. "But if people can get over it, it can be unbelievably rewarding."

Al Etmanski leans back in a wicker chair in his office at PLAN's Burnaby headquarters and puts one foot up on a small table. Sun pours through a fifth-floor window onto a shelf packed with pictures of his children. He's tall and at 53, grey hair is taking over his head and goatee.

Etmanski is a co-founder and acting executive director of PLAN and the father of a daughter with Down's Syndrome.

He and several local families first created PLAN in 1989 because they worried about what kind of life their children would have when they died.

"A number of us were beginning to see the limitations of programs and services for people with disabilities," says Etmanski, whose natural deep voice borders on the hypnotic. "What we realized was that for many people with disabilities, the only connection they had was with paid professionals."

Etmanski says real stable, lasting friendships, and the ability to make a contribution to society are of paramount importance in everyone's lives. But that's exactly what was missing in traditional programs that focused too much on a person's disability.

"There's this prevailing consciousness that [people with disabilities] need professionals to survive. It's like this bred dependence. They're made to feel like they're not capable of solving their own problems and that's just not the case."

Each PLAN member is assigned a facilitator who finds out their interests and passions before looking for people in the community who might be a good fit. The key, says Etmanski, is looking for a "click" and the grounds for a real friendship. "The introductions are always done on the basis of 'Okay here's somebody who's as interested in writing or opera or going to church as this person is,'" says Etmanski. "Then what we say is, 'Would you be interested in getting together once a month and discussing how to help Gordon realize his dreams and handle his challenges?' Then we see what happens. We never ask them if they're prepared to make a lifetime commitment to this person right off the bat."

Etmanski says the response, once a connection is made and the PLAN concept explained, is phenomenal. "We've got over 800 people who've made commitments to individuals with disabilities and they'd be very angry with me if I called them volunteers. They have a real relationship with the individual. The depth, the bond is phenomenal."

Etmanski estimates it costs \$3,000 in the first year to set up a network and \$1,000 every year after that—almost all of which pays for the facilitator's wages. Half the money comes from the families themselves, while the rest comes from the sale of PLAN's two books on living life with disabilities called *A Good Life* and *Safe and Secure*, and from charitable foundations, like The Vancouver Foundation.

Every year plan hosts the Celebration of Hearts: a banquet to honour PLAN members and their friends on the Saturday closest to Valentine's Day. About 300 people attend. Each circle of friends sets up its own table at the back of the room honouring its PLAN member. Last year, Walker's circle carved a two-foot-high wooden horse and covered it with pictures of him and his friends on a cattle drive he worked on in Kamloops last summer.

Cammack acts as the host and invites facilitators to come up to the podium and speak about their circles. "Last year Vickie invited Ryvr Tupper and a few of Gordon's circle up to the podium to speak," said Etmanski. "It was all planned in advance, but who comes up with them? Gordon...and he speaks too, in front of 300 people. It was awesome, just awesome."

For Etmanski, that's what PLAN does. It brings people out into the world and gives them a chance to thrive.

"It's like putting sunshine on plants. They surprise everyone, even their own families. They just come into themselves and it really shatters disability concepts. It's the most amazing experience. I can't describe it in words but I guarantee everyone in the room feels it."

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