

# OPINION

The Okanagan Sunday, October 18, 2009



File photo

The Haven House Society hopes to set up a group home for people with developmental disabilities in the Okanagan.

# Freedom, independence

# Freedom, independence and your own home

Most of us are blessed by having a roof over our heads. Others are not so lucky.

Many of us grew up with parents or caregivers ensuring that we were nurtured, did our homework and learned respect for others. We had an education of some sort, learned to negotiate by asking for more privileges and at some point were ready to leave the nest.

A lot of us moved out of our parents' homes as soon as we could in search of freedom.

We wanted to be able to watch TV when we wanted, turn the stereo up as loud as we wanted, go out with friends whenever we liked and sleep in whenever we wanted to. We wanted independence.

We may have felt fearless, we may have felt scared, but whatever we felt, we were starting a new chapter in adulthood.

Some may have gone away to school and stayed in residence, some may have shared accommodation with roommates. We were proud that we could care for ourselves, pay our bills (sometimes) and pay our rent (always).

We made money and bought our own food, cleaned up afterwards (perhaps), and were responsible for ourselves. Some of us learned to cook and (in some cases) eat it, too.

It was new, it was fun, and we were participating in the big world as adults. For most of us, those were the best days of our lives – even though they usually consisted of little or no money.

For people with disabilities, options for independence may be limited or nil. Depending on the level of care needed to live a "typical" life, independence is simply not an option for some.

We hope that most parents want to raise good citizens; people who want to live in a positive world with respect, independence and tolerance, regardless of whether they have a developmental disability.

Growing up 50 some years ago, many people who could moved out to join the workforce very early on. I moved out at 17 to travel, and many of my friends of similar ages did the same or went away to school. It was not typical to stay at home much past 20, but exceptions certainly happened and still do, as evidenced by our second son moving out at 25.

In all of our children's cases, we want them to move out when they are ready to take on the world – including our daughter with Down syndrome.

In Emma's case, as a high functioning person with Down syndrome, as with our other children, we have been teaching the skills that will be needed to one day move out.

That is a scarier prospect for parents of a child with a disability. She is more vulnerable, no matter how much we work with the great services provided to us through Community Living B.C.



ALLISON  
MCNEILL

## *Whose Challenge Is It Anyway?*

Emma has learned to take the bus and get to her classes at Okanagan College by herself, she can get to her programs at Access, go to a movie on the bus with her friends and to other outings. She can walk or ride her bike when going to and from work at the H2O Centre; she can meet her support worker for tea.

Don't forget to turn on your cellphones – they are lifesavers on the road to independence.

Our daughter is proud of herself and her independence – and so is the rest of our family. She is functioning in a typical world with typical people even though she will always live with her disability. She has in some ways overcome it.

Emma has her own suite in our house. It has been the responsibility that is teaching her the skills needed to eventually move out of our home into her own.

She does not have a kitchen, but she does have her own bedroom, living room and bathroom.

She needs to plan ahead for laundry, make and change her bed and balance TV watching with art, reading and music. She tidies and cleans her place weekly.

Emma shares in the duties in our family kitchen and cleans up, sets and clears the table, and helps purchase and put away groceries, just like a typical child in our home.

So, when she moves out, what are her options?

We have looked at several over the past four years.

Since going on to college, Emma has learned most of the skills for living outside the family home. In her case, her disability should allow her to have a fairly independent lifestyle.

A group of like-minded people has come together to look at all the many choices for young adults in similar situations.

We have formed a society called Haven House and are in the midst of a feasibility study to see if we can create a model that could help individuals live together in a positive, exciting, dignified way.

There have been many questions.

Should the house have room for 16 or 64 people? Should the suites all be wheelchair accessible? Should they have a swimming pool, gym

and theatre or build close to those services? Should we have a retail operation or farm on site to provide jobs and responsibility? Should we have a cross-section of elder people, typical people and people with a disability all living together? How do we pay for this? What if one person can afford their own suite and another cannot? Do we look at a life lease scenario or rent or respite?

On and on it goes, which led us to engage Cost Time Quality Consultants. CTQ has put together an online survey to poll what is needed in this region.

We hope that if we do this right, the housing concept can be a blueprint for other groups to work from. To do that, we need your input.

The survey takes only a few minutes to complete, but will allow us to determine the priorities and needs for housing in a blended scenario. Please take the time before Oct. 24 to go online and fill it in. Everyone's opinion is valuable.

We plan to have Haven House become a reality within the year.

You can find the survey at: [http://www.surveymonkey.com/s.aspx?sm=5c1PSyMm\\_2fm1iytVCTwgSSQ\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=5c1PSyMm_2fm1iytVCTwgSSQ_3d_3d)

## Upcoming events

**October is Community Living Month**, therefore, a really good time to look around your neighbourhood and become as inclusive as you can.

The Start With Hi program is a good place to begin. The program is all about acknowledging people with disabilities by just saying "Hi."

CLBC spoke with people with developmental disabilities about how they could feel safe in their day-to-day lives, and they had some great advice.

"If people would just say hi to us more maybe we would feel more included and feel like we had more people to ask for help if we needed it," was a typical response.

Some suggestions are to consider bringing an acquaintance with a disability fully into your community by volunteering, donating to a charity that supports people with developmental disabilities or employing a person with a disability.

CLBC-Okanagan is taking part in Start With Hi by distributing campaign material at Orchard Park Mall on Oct. 24. Please take time next Saturday to just say "Hi."

PLAN Okanagan is having its annual general meeting Oct. 26, 7 p.m., at 555 Fuller Ave.

A must go to if you are planning the future of a person with a disability.

**Allison McNeill is a mum to four, one of whom has a developmental disability, step-mum to two and happily married to all of their father! She is a Kelowna's 2009 Woman of the Year.**

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