

H.U.B.

HELPING U BELONG

Declaration of Support for Community Living

This Declaration of Support for Community Living can be accessed at:
www.institutionwatch.ca

WE, INDIVIDUALLY AND COLLECTIVELY, commit to working together to assist persons to return to their communities and call on all levels of government in this country to:

- Acknowledge that institutions for persons with intellectual disabilities have no place in today's society;
- Stop financing or otherwise supporting the establishment of new institutions for persons with intellectual disabilities;
- Stop all new admissions to existing institutions;
- Support the right of all people with disabilities to live in the community as equal citizens;
- Commit the necessary resources to support the development of quality, comprehensive community-based alternatives to institutional care;
- Acknowledge the wrongs that have been committed against those individuals who have been held for far too long in institutions across this country



Sticks and Stones Part 2

Sticks and stones may break my bones
But words will always hurt me.

You may act like it's nothing but
Inside it could hurt you deeply.

Vandalism, racism none of it's cool!
Bullying is something we don't want in our school.

Sticks and stones may break my bones
But words will always hurt me

By Joseph Lamey

We're on Facebook! 'Like' us in order to get updates about disability related info and news. And be sure to check out our website at halifaxacl.com

Fall 2011

Vol. 9 Issue 2

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Helping U Belong

We welcome your contributions to our newsletter. Please submit your ideas, articles or resources to us at:
exdirhacl@eastlink.ca

phone: 463-4752

fax: 463-5007

or mail:

2557 Maynard St.,
Halifax, NS,
B3K 3V6.



Aging Parents, Adult Children

Dealing with the reality of parents aging while trying to meet their ongoing responsibilities to care for and support a loved one with a disability can be emotionally and practically difficult. Parents who have been through these transitions have learned some lessons and offer their wisdom to others.

Plan for Change as Early as Possible

Planning for the time that you will not be the primary supporter should happen as early as possible. It is important to not wait until the last minute. If you have other children, involve them in the planning. Having a 'draft' plan can be useful even if you are not ready to put it into action. This gives you time to modify the plan if necessary. Putting plans into effect while you are still here allows you to oversee how things are going and to keep other people accountable.

"Think outside the box. Just because something isn't available doesn't mean you can't create it. Everything there is today is because a parent or parents got together and created it."

"Parents want perfection and guarantees. In real life, we can't re-create that outside the family relationship."

Being Able to Let Go

Letting go can be hard, but it is necessary. The alternative may be a crisis that will not offer or provide a good life for your son or daughter.

"It's okay to let go. You're still involved. You're still giving them quality time of yours, rather than quantities of time. And quality is better."

"I've been there and I know how you feel. But it does change. We've all been there, just do it gradually and you will be fine."

"The secret is finding the right place to let go. Find a comfortable fit and

it will be easy. Well, easier."

Don't Rely Only on Government

Government programs will be helpful in looking after basic needs and address some of your son's or daughter's needs for support. Life in the community involves much more. Your sons and daughters will need supportive relationships

and opportunities to contribute their gifts and talents. Help your son or daughter be connected to other people and activities in the community.

"Government looks after survival, not thriving."

"The secret is finding the right place to let go. Find a comfortable fit and it will be easy. Well, easier."

Having a Life of Your Own/Dealing with Loneliness

If you have been supporting your son or daughter for many years you may want to have time to yourself and enjoy other aspects of life. Feeling this way is perfectly natural.

"There will never be a perfect time. You reach the point of putting your needs, and time for yourself before your days are past, first."

"I will always be the girls' mother, but still, I want to be Leena. Not their mother all of the time."

At the same time, you may be concerned about being lonely if your son or daughter moves out. It seems that the

longer your adult child lives with you, the harder it is to change the living arrangement for both you and your adult child. As part of your planning consider how you can have opportunities to spend time with other people.

Dealing with Financial Realities

Sometimes parents and their sons and daughter with disability are dependent on each other financially. If your son or daughter were to leave the family home you may not be able to afford to live there yourself. Part of the planning process may involve how you can manage financially if you had to live by yourself. If you and your adult child need to live together for financial reasons, make sure that you have an emergency plan and, if possible, a plan for where your son or daughter will live in the future.

Seek Out Help and Support

Parents should not have to face these issues alone. You may need help with planning or with dealing with service systems in order to get the right support for your son or daughter. It may be important to not accept 'no' for an answer when you are looking for help. Organizations like the Association for Community Living may be able to help you deal with these issues. Seek out other families who are dealing with the similar issues to support one another.

For more information on issues facing aging parents and planning for the future, please refer to NBACL's *A Time of Change: An Information Guide for Senior Parents Supporting an Adult Son or Daughter with a Disability*. And if you would like support in planning for the time when you will no longer be the primary supporter of your adult child, please don't hesitate to call Lisa or Yvette at 463-4752.



Opportunity for Entrepreneurs with Disabilities

Are you an Entrepreneur with a Disability who has always wanted to test and/or sell your product to thousands of consumers?

Do you have a product that you feel would fit into the "Halifax Seaport Farmers' Market"? <http://halifaxfarmersmarket.com/>

At Entrepreneurs with Disabilities Network, they understand that it can be an enormous challenge to come up with the resources and supports needed to test and/or sell a product. EDN's new "Seaport Farmer's Market Program" assists entrepreneurs with many of these challenges, and helps get small businesses started successfully. EDN offers:

- Free membership to EDN and their resources.
- A 50% subsidy for their members' table(s) at the market.
- Assistance with display set-up, bookkeeping, business planning, marketing strategies and more.
- A storage location at the market for early drop offs and pick-ups.
- Opportunities for collaboration with other EDN members.
- Two beautiful display units 4 x 2.5 feet in size.

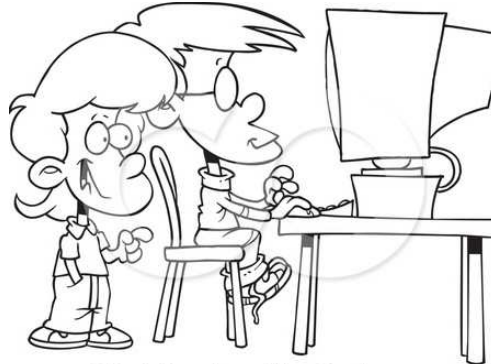
Space is limited and provided on a first come first serve basis!

If this program sounds like something you may be interested in, and to find out program requirements, please contact Archie Gillis, Business Counseling Coordinator at EDN:

[426-0591](tel:426-0591) archiegillis@ednns.ca,
www.ednns.ca,

Link Round-Up

www.AbilityOnline.org is a free and monitored internet community for young people with disabilities and illnesses. They offer discussion threads, chat facilities, and games and activities where kids can come together to have fun. Youth are able to meet and chat with other youth and supportive adults, and can address their needs for friendship, support, and information. The site also has a strong emphasis on safety and security – members can only register using their real names and contact info, and this identification is verified prior to site access. Public online messages are consistently monitored for appropriateness, there is zero tolerance for bullying, and all staff and volunteers at the site are police screened. The site provides opportunities for confidence building, skill development, and peer support, and provides mentors, homework help, and help with the transition to adulthood.



People with intellectual disabilities as subjects and performers remain marginalized in the media. The Sprout Film Festival aims to raise their profile by showcasing works of all genres featuring this population. They have uploaded many of these amazing films on their Youtube channel, which can be found at www.youtube.com/user/STFFestival

ZacBrowser.com is a free Internet browser designed to help children on the autism spectrum enjoy educational sites on the web. The browser is a 'full screen' program which can't access the task bar, the Start menu, and cancels out the right hand function of the mouse. This makes it much easier to use as the buttons are limited to essential functions. The browser is set up to prevent users from accessing inappropriate websites while allowing them to access a large selection of games, activities, and videos that have been chosen to provide a positive experience for children with autism.

Best Buddies

Best Buddies is a national organization dedicated to enhancing our communities through one-to-one friendships between people with intellectual disabilities and students. Best Buddies establishes chapters at high schools, universities and colleges across the country, and there are a number of chapters in Halifax. At each chapter students are matched with people with intellectual disabilities who share similar interests. This might be an interest in music, or a love of sports, for example. The "Buddy Pairs" call each other weekly and get together approximately twice a month. In addition to being matched up in a one-on-one equal friendship, buddies with and without intellectual disabilities will come together over the course of the year and enjoy group activities. These group activities provide opportunities for all the buddies involved to get to know one another. HAACL is a host organization for Best Buddies, and helps find people with intellectual disabilities who want to be matched with a peer buddy. Interested? Then call or email Lisa (463-4752, lagarrett@eastlink.ca) to find out more and to start the application process. For more information about the program, check out www.bestbuddies.ca



New Staff at HA CL

My name is Andrea Urquhart and I am excited to be joining the HA CL team as the Preschool Director. I worked in the early childhood educator field for over 12 years and I'm looking forward to starting new adventures with the Halifax Developmental Centre for Early Learning!



I studied at Queen's University, Saint Lawrence College, and Mount Saint Vincent University. I have an Early Childhood Education diploma and a Child & Youth Studies degree, and hope to someday pursue a Master's degree in Speech Pathology. I began my career in the child care field in Kingston, Ontario running a before and after school program, and providing one-on-one support for a high-needs Grade 7 student. I moved back to Nova Scotia and worked in a developmental centre as a Preschool teacher, and then went on to become a Preschool Director/Teacher in a community resource centre. In my most current position I worked as a Parenting Consultant and Adult Program Facilitator with the military community. This was a new challenge for me, but one I thoroughly enjoyed. I am very happy to re-enter the child care field with the amazing staff we have at our Centre!

I am also a mom to a 2-year-old little girl and look forward to having her attend the Centre to get to know all the great children we have registered and benefit from the excellent programming the staff provide each day. I am also looking forward to connecting with all the families and board members to create partnerships to support our Centre as it grows and progresses. This is an amazing organization and I'm so proud to be a part of it!

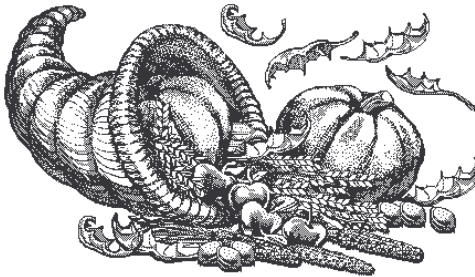
Hello HA CL Families and Friends!

My name is Yvette Cherry, and I am one of the new Family Support Facilitators. Some background about me: I have two psychology degrees one from St.F.X.U. and one from the Mount. I have worked for l'Arche, Regional Residential Services Society and Dartmouth Adult Service Centre. However, my most valuable experience with intellectual disabilities began around 1998 when I received news that my son had a developmental delay. Soon after that, I became associated with H.A.C.L. through the Family Support program. My facilitator helped me become a successful mom advocate for my son and my family. She asked me to share my story with other mom's and even education students at Mount St. Vincent University. I occasionally wrote articles for the newsletter and joined in on a Breakfast Television interview with H.A.C.L. and my children.



I joined the Board of Directors for H.A.C.L. in 2009. In the spring of this year, the Family Support position became vacant and I began volunteering in the role one day per week, while still serving on the Board. My term on the Board ended in June 2011 and I applied for the Family Support position. And here I am!

I am looking forward to working with you and your families!



My name is Lisa Garrett, and I'm joining HA CL as a Family Support Facilitator. I'm really excited about my new position, and feel very strongly that disability rights are an important part of social justice work.



I moved to Nova Scotia from Ontario in 2003 in order to attend the University of King's College. I graduated in 2007 with a degree in Contemporary Studies and Gender and Women's Studies. After graduating, I moved to l'Arche Cape Breton where I was a live-in assistant in a home for adults with intellectual disabilities. I developed many close friendships with the folks I lived with, and still maintain contact with several of my friends there. After leaving l'Arche, I moved to Antigonish in order to do an internship at the Antigonish Women's Resource Centre. While there, I worked on a violence prevention project for young rural women, and developed resources for service providers who work with youth and a resource directory for young women. After completing my internship, I moved back to Halifax and found work at Adsum House, a shelter for women experiencing homelessness. I provided front-line support and facilitated recreational programming for the women accessing services. Last year, I enrolled in a Masters program in Women's Studies and Feminist Research at the University of Western Ontario. Throughout my program, I focused on disability studies for several of my projects. I completed my program in August 2011, and moved back to Halifax in September, when I began my position here at HA CL.

I'm excited to join the HA CL team, and am looking forward to helping families and individuals advocate for the supports they need.

Diploma in Intellectual Disability Studies

St. Francis Xavier University offers the *Diploma in Intellectual Disability Studies* by distance education (online) to adults who care for people with intellectual disability. Current participants include parents of children/adults who have an intellectual disability, L'Arche assistants, group home leaders and workers, residential care facility coordinators, employment counselors, residential counselors, teaching assistants, and CACL staff.

Taking part in online asynchronous (anytime/anywhere) discussion with classmates and instructors is required. The diploma is a progressive way of addressing some of the toughest challenges in the field of intellectual disability and the online discussion is an excellent forum for combining education and experience in the field. Coming from a variety of backgrounds, the participants in the program share from the richness of their first hand experience.

Participants must have a minimum Grade XII academic and one year experience working or living with a person who has intellectual disability. Those who do not have Grade XII may qualify under the Mature Student Policy. There are no exams in these non-credit courses but there are two written assignments per course.

Tuition is \$500 per course plus textbooks, course packs, etc. and average \$75 to \$130 per course. Payment plans for tuition can be set up and a minimum, non-refundable down payment of \$150 is required with each course registration.

Courses include:

INDS 110: Foundations of Disability and Caregiving

INDS 120: Relationships, Advocacy and Vision

INDS 130: Human Development

INDS 140: Building Community

INDS 150: Practicum

Applications are accepted for the fall and winter terms on a first come, first served basis. Course details and other information can be found online at:

www.sites.stfx.ca/continuingeducation/INDS. Tel: 902-867-4696 or toll free (within North America) 1-866-551-7575, Fax: 902-867-5154, Email: inds@stfx.ca.



Scouting Out Work Opportunities for Your Teen

From www.hollandbloorview.ca

Many teens get their first part-time job through their parents' efforts.

* Reach out to friends, teachers, colleagues, local businesses, your faith community and family to come up with work or ideas for innovative work-related activities.

* Visit businesses and organizations related to your child's interests. Tell them about your child's strengths and abilities. If an employer shows an interest, call back later to set up an interview.

* If your adolescent is in a transition program which provides on-site job coaching, be sure to mention it. Knowing that a job coach will work with your child on the job makes it easier for an employer to say yes.

* Raise your adolescent's profile in your neighbourhood. Get to know the people at your place of worship, grocery store and video store. All are potential employers. The more familiar they are with you and your child, the better a chance of a job opportunity in the future.

* Community centres are a good source of volunteer and part-time jobs. Get to know your community centre as a family when your adolescent is young.

* Odd jobs can be found close to home. Neighbours may need someone to water their plants or feed their cat while they're away.

When you find a position for your adolescent, make sure that the employer and the people your teen will be working with are educated about the disability in advance.



Protecting Your Child's Future with the Henson Trust

By Michelle Morgan-Coole

Last Spring, we read an article in HUB newsletter about the importance of having a Will.

Wills give lots of people the willies—only 70% of Canadians have in fact written a will. Some people procrastinate, while others find the idea too morbid. But dying without a will is not advised—hence the saying: —A person without a will has lawyers for heirs.

But what we didn't read was the nuts and bolts of why a Will is even more important when you have a family member with a disability AND how your Will must be different than your neighbour's or relative's when there is a family member with a disability. To say nothing of the potentially dismal consequences should you fail to heed those words of warning.

The Henson Trust

The **Henson Trust** was named after an Ontario man who wanted to pass his entire estate onto his disabled daughter. But, unlike many, he realized that if she became the sole beneficiary of the estate and therefore "owned" significant assets and/or property, the government would consider her ineligible for any social assistance payments. Meaning that, if she lived in Nova Scotia, for example, she would be ineligible for any of those programs under the Province's Services for Persons with Disabilities Program.

For this reason, Mr. Henson drafted his will so that his entire estate was transferred to three trustees to be held on his daughter's behalf. The trustees had the discretion to withhold or spend the income and capital to best serve the daughter's interests. For example, money from the estate could be used to buy her a TV or new clothes or pay for a chaperoned trip. And because these

payments were considered discretionary benefits, she still qualified for government support.

What the Will didn't do was give the daughter a legal claim to demand money. Unlike the traditional trust that parents often set up for their minor children, Henson's daughter would never be in a position to go to court and claim that the trustees were wrongfully withholding trust monies from her. But it was precisely because she had no legal claim to the monies that the government could not treat the money as hers after she inherited it.

The trust that Mr. Henson set up has come to be known as a "**Henson Trust**" and now lawyers across the country have access to a vehicle that they can use in nearly every province to ensure that their clients can provide for their child without the loss of government benefits.

That, however, is not what you're likely to hear from Nova Scotia's Department of Community Services - if questioned, they are likely to tell you that a Henson Trust is a waste of time and money as any money left in a discretionary trust will result in the beneficiary being ineligible for benefits under the *Employment Support and Income Assistance Act*, meaning ineligible for services under the Province's Services for Persons with Disabilities Program.

Ask a knowledgeable lawyer, however, and you will get a very different response. **Although the issue has yet to be tested in court in Nova Scotia, the consensus of legal opinion is quite confident that, were it to be taken to court, the Henson Trust would not affect the beneficiary's access to government programs.**

What makes the **Henson Trust** effective is the fact that the trustees are given full blown "absolute and unfettered" discretion to distribute the estate's income and capital to the beneficiary as they see fit. From a legal point of view, this means that the beneficiary gains no vested right to income or capital under the trust. She cannot claim payments from the

trust, she cannot demand them, and she does not, as a result, own the contents of the trust.

And it means that, *theoretically at least, the Trustee could decide to never disburse any money from the trust to your child and there would be nothing that anyone could do about it.* For this reason, you will want to choose your Trustee with great care. You are giving them an immense amount of power over your child's life.

This requirement of "absolute and unfettered" discretion has resulted in the need for that Wills be worded, not just correctly, but precisely correctly. The Will must be worded to provide **complete** discretion to pay out or withhold income and capital. Almost by the use of "*magic words*". "*Magic words*" that your lawyer needs to know. And, unfortunately, although the situation is improving, it would appear that many lawyers are unaware of the need for these "*magic words*" or even their very existence.

And although there is much more that could (and should) be written about the Henson Trust, the most important thing you can take away from this article is two-fold:

- 1. The traditional trust arrangement will not allow your disabled child to continue to receive government benefits after your death. Only a Henson Trust will accomplish this.** This is because the typical discretionary trust is caught by sec. 58 of the Regulations made under the *Employment Support and Income Assistance Act* and will thus end your child's right to obtain social assistance or other benefits under the Services for Persons with Disabilities Program until the trust fund has been depleted.
- 2. The onus is on you, as the parent or guardian, to ensure that you locate and retain counsel that is competent in the**

Continued Page 7

Nicky's Icy Treats: Taking Matters Into Your Own Hands Through Employment Partnership

By Mariette McDonald

Looking for a summer job can be a daunting and disappointing task for any youth especially with our current tough economic situation. Add a severe disability to the mix and you have a recipe sure to fall short of goals and ambitions for these youth and their families.

Potential employers are looking for employees that can improve the bottom line. No one is ready to hire a student, with or without a disability, out of the goodness of their heart. Added costs such as having to add a ramp, automatic door opener, space, etc, all deter employers from hiring youth with disabilities. The more severe the disability the more difficult it becomes to integrate and include these youth in summer jobs.

In the summer of 2010 I decided to take matters into my own hands and in the early spring months I began formulating a plan.

We approached the project of a summer job by creating an Employment Training Skills Program for youth with disabilities in the community.

Partnership was the key to the success of this project. A Job Coach was hired and 5 youth participated in the program teaching employable skills, earning a bit of money and providing a meaningful

"As the summer of 2011 was looming Nicole and I were once again thinking about what we could do for a summer job. Could we take the idea from last summer and somehow weave the idea more intricately into our community?"

activity for the summer selling ice cream products at the local recreation centre. While no one walked away rich, the project was a huge success.

As the summer of 2011 was looming Nicole and I were once again thinking about what we could do for a summer job. Could we take the idea from last summer and somehow weave the idea more intricately into our community? After all, one of our goals was to generate awareness that people with disabilities can be valuable employees.

First I scouted out our community searching for an ideal location that would allow Nicole to set up her Ice Cream Business at a minimum cost. I approached a Community Business to act as a partner or sponsor to collaborate with me (and Nicole) to provide some type of employment for her for July and August of 2011. We already had the equipment, signage and uniforms from the previous summer. The owner of Delish Deli and Cafe in Tantallon thought it was a great idea and was very supportive, going so far as to install an outdoor outlet for us to plug in the freezer.

Nicole did not need to be employed by the Business Partner but kept profits from her sales as her income. She ran her business separately from Delish and set up outside, with picnic tables and umbrellas on days when she was available. As part of the collaboration we also suggested that she could work out a schedule best suitable to the business partner and volunteered to clear off tables and do general tidy up.

This turned out to be unnecessary but could be a nice touch depending on the situation.

Our partnership was

not limited to just our location at Delish Deli. A small commercial freezer was provided to us by a contractor, freezer space for our inventory was provided by another business next door and a small amount of printing of menus was donated.

Our proposal letter and partnership idea was used by another group in Halifax and a local SuperStore. As more and more families become touched and involved with loved ones affected by disability, more and more businesses are willing to help. When approached with the suggestion to support these types of projects, allowing individuals with disabilities to be engaged in community as opposed to taking on the full responsibility of employees, most are interested in helping out.

I think people really do care, we just have to think of a way to allow them to show it.

Think! Plan! Propose and ASK, ASK, ASK!

Henson Trust Continued

use of the provisions of a Henson Trust. Unfortunately, this is a situation where, if it's "done wrong", it will not be discovered until after your death. And while you, personally, will remain blissfully unaware of any problem, it will be your beneficiary who will pay the price.

As always, nothing written here is meant to be taken as legal advice or opinion. It is only general information. Always consult with a lawyer as to the specifics of your individual family situation.



Halifax Association for Community Living

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Halifax Developmental Centre
for Early Learning
423-4702

Family Support
463-4752



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Statement of Disclaimer:

The HACL feels morally obligated to share any information brought to our attention that may benefit, or be of interest to, our readers. However, the HACL does not necessarily endorse all the articles presented.

Mark Your Calendars

October 21-23 Halifax, NS Canadian Association for Community Living *LIVING IN COMMUNITY- THE MANY FACES OF INCLUSION CONFERENCE 2011* will be co-hosted with Nova Scotia Association for Community Living and held at Atlantica Hotel Halifax, Halifax, Nova Scotia. This conference will offer sessions and discussions on the many ways in which persons with intellectual disabilities can assume their rightful place in community, and the role that we, as family, friends, and advocates, can play in helping make that happen. For more information, visit www.nsacl.ca

October 28, Horton High School, Greenwich NS, Tools for Life Conference and Exhibit 2011: A day of free public educational sessions and exhibits. Over 70 educational sessions, 100 exhibitions, and an inclusive employment and career fair. No admission required. Pre-registration is encouraged, and the registration form can be found at www.tools4life.ca

October 2011 at The Drop In Club, St James Anglican Church Hall: The Drop In Club has a bunch of great events planned for October. The Club is open to those 12 and older, and you can check out their Facebook page to keep up-to-date about what they have planned—just search for ‘SCRI Society The Club Facebook’. On October 14 from 7pm-9pm they’ll be doing African Drumming and Dance, and on October 28 from 7pm-9pm they’re having a Halloween Party.

November 1-7: National Down Syndrome Awareness Week
www.novascotiadownsyndromesociety.com

November 26 Guardianship and Henson Trust Information Session, Keshen Goodman Library, 2-4pm. Learn more about Guardianship and the Henson Trust as it relates to your son or daughter with an intellectual disability. In Nova Scotia, every person ceases to be a minor when they attain the age of 19, meaning that, as a parent, you have no legal say in your adult child’s life. In law, a “guardian” is a word used to describe a person who has the care or custody of another individual and who has the legal duty to provide for that individual. Not every individual with an intellectual disability will require a guardian. How will you know if your family member does? What options are available for a parent seeking guardianship or simply the ability to act as their child’s legal representative in some matters? Can a guardianship application be done on your own, without hiring a lawyer? Come hear Michelle Morgan-Coole, a non practicing lawyer and also a parent of a child with special needs, explain the law of guardianship and supported decision-making in Nova Scotia.

November 26 Prescott Group’s 10th Annual Tea and Sale, 3430 and 3480 Prescott Street, 10am-2pm. There will be a silent auction, raffle and bake sale. Come for crafts, Prescott products, baked goods, New to You, seafood chowder or chilli, and coffee or tea and dessert.

