

H-CARDD 101:

What is the Health Care Access Research & Developmental Disabilities Program doing that could be relevant to your family?

In this brief introductory document, we want to share some information about our Ontario based program called “H-CARDD”, Health Care Access Research and Developmental Disabilities. We have learned that adults with developmental disabilities experience more health problems, and have more health care use than other adults. Since 2013, H-CARDD has been “digging deeper” to understand more about certain subgroups (women, aging adults, young adults, and adults with mental health or addiction issues). We are also testing out some solutions, and learning about what works and what doesn’t with a focus on *primary care* and *emergency care*. Information on all of these projects can be found on our website, www.hcardd.ca

1. The H-CARDD Atlas

Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario



[The H-CARDD Atlas](#) gives the big picture on health care and developmental disabilities for over 66,000 adults in our province. You can read the first chapter of the atlas for a great overview of healthcare issues and the last chapter which pulls it all together. Chapter topics include health profiles and health care use, preventive care, chronic disease management and medication use. You can also read [research snapshots](#) which summarize each chapter of the atlas.

If you want to talk about findings from the Atlas (the big picture) with your family, you can watch [this video](#) together online where the H-CARDD Program Director explains the report to families.

2. Four Vulnerable Subpopulations

Right now, we are taking a closer look at **4 vulnerable subpopulations** from our original research with projects focusing on: **women, young adults transitioning from children’s to adult services, individuals with mental illness or addictions, and aging adults**. Each of these projects has done a virtual town hall which you can learn more about by visiting their webpages (see next page):

- [Mental Illness and Addictions](#)
- [Women's Health](#)
- [Transition Age Youth](#)
- [Aging](#)



Three of the projects have also developed Applied Health Research Question reports that might be of interest, available on our [website](#) and the AHRQ section [below](#).

- [Aging and Frailty](#)
- [Addictions](#)
- [Young Adults with Autism](#)

Which findings from these projects are most relevant to you? How else would you like to get information on what we have been learning about these 4 vulnerable groups of adults?

3. Improving Primary Care



We are doing some important research on how to improve primary care. Our focus has been on **improving rates of the annual “health check.”** We are close to completing one project where we have looked at how to get Family Health Teams to give “health checks” to their patients with developmental disabilities. We have studied the benefits of this approach, to the team and to the patients. As part of this project, we share a number of [tools](#) developed through the Developmental Disabilities Primary Care Initiative (DDPCI) with family health teams along with some other clinical tools to help the [care team](#) and [patients](#). We have also started another project focused on getting more adults with developmental disabilities to go to their family doctor to ask for a health check - Stay tuned for more information on that project.

[These tools](#) were developed specifically for caregivers and together with the tools for primary care providers, they can help to improve primary care. Are you familiar with these tools? We want to hear what you think about these tools and what other tools might be of interest to your family (note: that all of the tools on the primary care website are available in French and English).

4. Improving Emergency Care



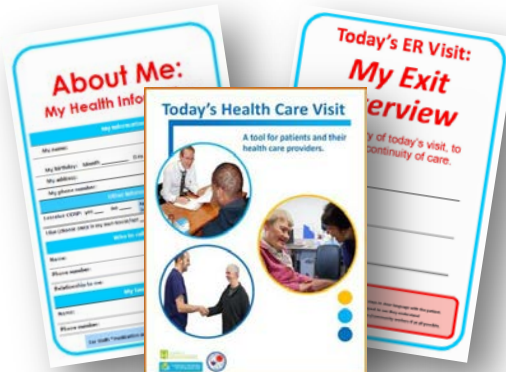
We are doing some important research on **how to improve emergency care**. This is because we know emergency use is much higher for those with developmental disabilities than for those without. We are almost finished a project where we have tried to get 3 emergency departments to improve how they support patients with developmental disabilities. As part of this project, we developed a number of [clinical tools to help hospital staff](#) as well as some [communication tools for patients](#) and their [caregivers](#).

A big lesson from this work is about preparing for emergencies and working collaboratively with hospitals to do so. We have written resources in addition to some helpful videos that speak to some of these issues. Is your family prepared for emergencies? Do you have easy to access information that can go to the hospital easily when there is an emergency? Remember that hospitals need current information that is summarized and easy to review. They do not always have time in an emergency to go through very detailed binders.

5. Communication Tools

From the consumer's perspective: it is very important that we communicate our health issues clearly to health care providers. We have some tools to help us do this:

[Today's Health Visit](#)
[About Me Passport](#)
[Exit Interview](#)



These 3 tools were designed to empower individuals to be able to speak for themselves as much as possible.

These tools were designed to foster improved communication with health care providers. Do you have a preferred tool? Share it with us and let us know which communication tools you find most helpful and why.

6. Applied Health Research Questions (AHRQs)

We work on separate projects related to our main projects called Applied Health Research Questions, also known as **AHRQs**. You can find [summaries of findings](#) from our AHRQs on our website in plain language and if you click on a project, you can also read about it in more detail.

7. Newsletters



We have been working with [Vita Community Services](#) and [HANDS the Family Help Network.ca](#) to develop **staff newsletters on health topics** where we combine some key research findings with specific recommendations and tools. These newsletters are easy to read and tailored for staff. Topics so far include:

Women's health Medications Poop Men's health

In October, we modified our article on medications for families and it was published in Autism Matters. We are in the planning stages of developing newsletters on some of our more recent work. Is there a health topic you want to read more about?

8. Knowledge Exchange

Is the work of H-CARDD important to you and your family?

Join the H-CARDD community on Facebook or follow H-CARDD Twitter. Share the website link (www.hcardd.ca) and resources with others. Here you can read about what H-CARDD is learning, watch some of the videos, and tell H-CARDD what you think! The most important learning comes from these sorts of dialogues.



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