



## The Nuts and Bolts of Health Care: Training Direct Support Professionals to be Effective Health Care Advocates

### What is the project about?

Adults with developmental disabilities (DD) have complex health care needs yet experience great difficulties in accessing proper health care.

Direct support professionals (DSPs) work directly with people with DD to support them in day-to-day life, including navigating and interacting with the health care system. However, facilitating good health care remains a challenge for DSPs.

The Nuts and Bolts of Health Care Project is a partnership between H-CARDD and Vita Community Living Services (CLS) to help DSPs better support the health and health care needs of people with DD by:

- increasing knowledge about the health care needs of adults with DD; and,
- helping DSPs to effectively communicate with health care providers.

### What did we do?

Based on an Implementation Science (IS) framework, this two-year project used a 4-stage change approach to identify key gaps in current practices; develop/redesign tools and training; trial and refine the new resources; and embed resources into routine use.

**Stage 1:** The implementation team met with 60 DSPs, 14 supervisors/directors, 27 adults with DD, 2 pharmacists, and 6 physicians to identify key gaps in knowledge and skills related to the health and health care needs of adults with DD, and interacting with the health care system.

**Stage 2:** Based on Stage 1 feedback, DSPs worked together with the Nuts and Bolts team to review existing tools and develop new tools and videos to support DSPs in their work with people with DD.

### What you need to know

DSPs play a key role in supporting adults with developmental disabilities (DD) to manage their health. The Nuts and Bolts of Health Care team worked collaboratively with DSPs to create a set of tools, videos, and resources that meet their needs and can be incorporated into routine practice. The Nuts and Bolts Toolkit is available to community agencies to help DSPs be more effective health care advocates for people with DD.

**Stage 3:** The team developed two tools: [About My Health](#) and [My Health Care Visit](#). In addition, the [Nuts and Bolts Toolkit](#) was developed, with key information, tools, monitoring charts, and videos.

The new tools were introduced into practice using a train-the-trainer model, in which a core group of DSPs and supervisors were prepared to provide training to all DSPs on the new tools. DSPs provided feedback, which led to further modifications.

**Stage 4:** Full implementation of Toolkit resources into routine practice, with resources posted online.

### What did we learn?

A comprehensive evaluation was conducted, including a staff-wide survey, file audit, staff focus groups, and interviews with people following a health care visit. Staff feedback indicated that the tools were feasible to complete and helped with preparing for health care visits, providing support in the waiting room, communicating with health providers, and post visit follow-up. Even experienced staff reported that they learned new things about the people they support, such as health concerns that would not otherwise have come up.

## About H-CARDD

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program that aims to enhance the overall health and well-being of people with developmental disabilities through improved health care policy and services.

H-CARDD research is conducted by dedicated teams of scientists, policymakers, health care providers, people with disabilities and families working collaboratively.

For this project, H-CARDD partnered with Vita Community Living Services (CLS), a non-profit community organization that provides services to adults with DD and dual diagnosis (DD accompanied by a mental health need). Vita CLS provides residential supports, treatment programs, respite programs, and community participation programs, as well as clinical and educational services.

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## Toolkit Citation

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## What did we learn? (continued)

Completing the tools also helped adults with DD become more aware, prepared, and involved in their health care visits. The tools provided important information to health care providers, which improved communication with the patient and the staff. The tools also helped to identify all of the health issues to address, and generally improved the quality of the health care visit.

One challenge identified was that some health care providers perceived the My Health Care Visit tool to be lengthy and time-consuming to complete. This was addressed by condensing the tool, and efforts were made to embed it into electronic medical records. Moving forward, it will be important to work closely with health care providers and DSPs to ensure the tools are valuable and feasible.

## How can you use this research?

The Nuts and Bolts of Health Care Toolkit is available for use across Ontario and elsewhere. This toolkit has information for DSPs as well as for the people they support. To access the toolkit online, please visit [www.nutsandboltstools.com](http://www.nutsandboltstools.com).



## About the team:

The Nuts and Bolts of Health Care Project is a collaboration between the H-CARDD team at CAMH and Vita Community Living Services (CLS). You can learn more about the team [here](#).

## With special thanks to:

[The Developmental Disabilities Primary Care Program](#) at Surrey Place for collaboration on the About My Health and My Health Care Visit tools.

[Vita Community Living Services](#) implementation team, trainers, staff who worked on the project, and members who helped develop the Nuts and Bolts of Health Care Toolkit.

[The National Alliance of Direct Support Professionals](#) for helping to share information with direct support professionals across North America.

## Do you want to know more/additional resources?

You can find more information about this project and other H-CARDD research at [www.hcardd.ca](http://www.hcardd.ca).

Watch the Nuts and Bolts videos, [here](#) and [here](#), to see examples of strategies Julie and Kerry Ann use to help prepare for a visit to the doctor and how to make it go more smoothly.

