From Research to Practice:
Improving the Emergency Care of Adults with Developmental Disabilities – DD CARES

In recent years, an expansive body of research has been developed, studying the health care access, outcomes and experiences of adults with developmental disabilities in Ontario.

Research efforts have included the study of population-based administrative health data, hospital chart reviews, interviews with health care providers, patients and their caregivers, and the collection of community-based data. These efforts have resulted in numerous publications, presentations and knowledge transfer activities, all of which are aimed at using the results and learning from the research to inform policy, practice and, ultimately, to improve the care and quality of life of this vulnerable patient group.

This *Evidence in Action* will profile one of the knowledge transfer activities stemming from this body of work, notably an initiative focused on emergency care, *DD CARES*. Led by Dr. Jacques Lee at Sunnybrook Health Sciences Centre, DD CARES is an exciting partnership with the Dual Diagnosis Program at the Centre for Addiction and Mental Health (CAMH).

This *Evidence in Action* will give an overview of the implementation efforts and activities of DD CARES.

Continue reading to learn more about it!

This article was completed as part of a Community of Interest (CoI) focused on Dual Diagnosis.

This CoI is hosted by the Community Networks of Specialized Care-Central Region and has representation from a number of agencies and geographic perspectives.

For additional information on the CoI, please contact:

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What Evidence is being implemented?

A series of projects were conducted between 2005 and 2011, examining the emergency experiences of adults with developmental disabilities (DD) in Ontario (see references, pg. 6). From the research findings, the team has learned how often individuals with DD visit the ED, the most common reasons for these visits, and what the experience is like for each of patients, caregivers and ED staff. The team also has some ideas about what can prevent a repeat ED visit, based on the research.

Here are some of the key findings:

- Adults with DD are more likely to go to the ED than the general population:

    ○ One in two adults with DD will go to the ED in a two-year period,

    ○ And they are more likely to go frequently.

- The presence of DD is often not captured in the hospital chart. This means important supports, accommodations and assessment strategies can be missed.

- Patients, caregivers and staff report dissatisfaction during ED visits:

    ○ Patients' needs can go unmet;

    ○ Caregivers are not always consulted;

    ○ Staff feels ill-equipped to support this patient population.

- Repeat ED visits may be prevented with:

    ○ Comprehensive and collaborative crisis planning;

    ○ Enhanced continuity of care between ED and primary care.

As Dr. Yona Lunsky, Clinician Scientist in the Dual Diagnosis Program, says, "*We know that people with DD are likely to go to the ED. As such, we should be working to help these future patients and their future ED care providers to ensure that the visit goes as optimally as possible. We should also try to use these ED visits as a chance to put the right strategies, supports and plans in place so that we can minimize the likelihood of a repeat visit.*"

How did this work move from research to action?

A team with expertise in developmental disabilities, emergency medicine, and knowledge translation (KT) was convened and together they applied for funding for this KT project. A team of onsite, internal champions at Sunnybrook was also identified and together they began the efforts of putting tools, resources and strategies in place. The funding enabled travel to and from the pilot site, paid for the cost to design and print materials, paid for staff incentives, and supported staff time to work on this project.

Susan Morris (CAMH) seeks input on DD CARES tools during a launch event at Sunnybrook.

Is there a specific theory or framework being used to guide the work?

The team is using CIHR's *Knowledge-to-Action* cycle as a guiding theory, given its focus on applying and adapting information from research to an identifiable problem. Lunsky further explains, *"We've got the research that shows us that people with DD go to the ED a lot. We have our own ideas on how we can improve the care they receive when they arrive, and how to prevent, or minimize, the rates of repeat visits, but the challenge is how to get all the staff in a busy hospital environment to change how they support a population that they don't see that frequently. We need them to guide us on what they need to make their job easier and where to put the information so it will be used. We have ideas on what we think the tools and resources could look like and how they could function, but they will be minimal if we don't consider how they need to be customized to meet the needs of Sunnybrook."*

Implementation Science (IS) has shown itself to be a useful framework as the work moves through the Knowledge-to-Action cycle. IS proposes four key stages that teams must work through to foster a successful process for the implementation efforts (Fixsen et al. 2005).

So what is being implemented?

The project team is working with Sunnybrook to refine and implement a package of tools, clinical strategies and guidelines, relevant through the continuum of the visit (triage to discharge). These materials have been compiled from a range of

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DD CARES Implementation approach:

Exploration

Meet with Sunnybrook to discuss idea for project; convene a team of local champions; learn their processes and work flows; see what the needs are; discuss ideas for tools; see how to adapt them.

Installation

Refine and adapt tools, figure out where they will be used in the ED; work with IT and education to create online spaces; address barriers. Work with community partners to gather information the hospital is seeking.

Initial Implementation

Hold a 'launch day' in the ED to raise awareness of the project and to share the tools. Get more feedback, further refine the tools and share them for use in the ED. Hold several smaller meetings with specific disciplines and individuals to further use of the tools.

Full Implementation

We aren't quite here yet, but this would be when the resources and tools are used broadly in the ED and in other EDs – this is something we will be working towards in future stages.

Paul Sinclair, Administration Coordinator (Sunnybrook) and Dr. Yona Lunsky (CAMH) discuss a patient tool during the Launch Day.

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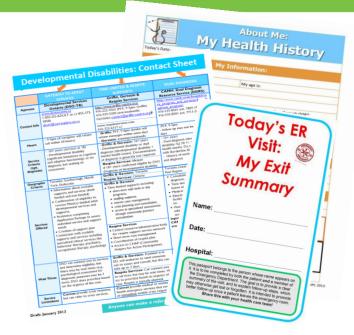Evidence Exchange Network
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sources, including the Developmental Disabilities Primary Care Initiative (2011), or created specifically for this project. They include:

Tools:

- **Hospital Passports:** This communication tool will help staff to better understand presenting issues, medications and strategies to use with the patient.

- **Discharge Summary:** This patient tool will communicate what happened at the ED in concrete steps and language and what follow-up pieces are needed. It can be shared with the community health providers, as well as the patient.

- **Discharge Packages:** These will include a range of patient materials and information on community resources.

- **Crisis Plans:** Templates for crisis plans will be given to patients and caregivers as part of the discharge package, to help them plan ahead in case there is another crisis.

- **Clinical Tips and Education:**
  - Recognizing DD
  - DD CARES Top 10
  - Assessment and Management Tools

- **Education (rounds, e-learning)**

Has there been any learning throughout the implementation process?

One of the big messages so far is that to facilitate change as an outside agency (CAMH) into a busy emergency department (Sunnybrook), it will take time, and it will take having great internal champions who believe in the work and share in the goal of improving emergency care for people with DD.

It's really helpful to have an internal team of people – even if it's just two or three – who work in the ED, and can tell you what's feasible, what's a good idea and what's important. Dr. Jacques Lee, Director of Research, Sunnybrook Emergency Services, explains it quite well. *"There's no time to do a lot of thinking on the floor in the ED – you have to do your thinking BEFORE you run into a crisis. Work out your processes changes ahead of time."*

It's valuable to engage and ask questions of the many people who play important roles in supporting practice change. On this project, this has included patient registration clerks, IT, managers, front-line nurses and social workers, the physicians and, in particular, those staff who play education roles in the department. These questions need to be very specific, walking through a situation or processing with an example patient.

Finally, EDs are very busy environments, where emergencies happen regularly. Meetings can be planned, but they may get postponed if a crisis presents, so it helps to be flexible and to allow for additional time to get things done. Information needs to be made available in multiple formats, with planning and feedback conversations (individuals and small groups) on the floor.

We also know that EDs see a whole range of patients, including other vulnerable patient groups, so figuring out how our efforts for the DD population can benefit these other patients has been an important "value added" of the project. The more our efforts can be applied by staff in their work more broadly, the better the uptake.

How will the implementation efforts be evaluated?

Several different survey measures will be used to evaluate the utility and benefit of the initiative from the ED staff perspective. This will give us information on how staff found the tools, the implementation process, and whether their attitudes and skillsets towards working with people with DD have changed.

We will also receive input and evaluative information as we implement and can see what tools get used and when, as well as what tools don't get used and why.

As DD CARES continues and evolves, we'll also evaluate some of the more long-term impacts on the emergency rates and experiences of people with DD in Ontario.

What's next for DD CARES?

DD CARES will be expanding to other sites and linking up with a parallel initiative led out of Queen's University, focused on the care of patients with DD in the Family Health Team environment. This should help to further enhance the continuity between ED and primary care, in the hopes of improving care at these important health care junctures.

The hope is that by implementing this work at multiple sites, an understanding of how to do this work well will develop so that an implementation strategy for the province can be developed.

As the project continues, it will also work closely with people with DD and their caregivers to ensure that the tools are relevant, not just for health care providers, but also for the patients and families. There are some really exciting ideas for this part of the work, so stay tuned to find out more!

In the meantime, please visit *www.ddcares.ca* for more information!

For additional information on DD CARES, please contact Dr. Yona Lunsky at yona.lunsky@camh.ca.

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The Evidence on which DD CARES is based:

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