



Reaching People Living with Diabetes: A Community Engagement Approach

The number of Ontarians with diabetes has increased by 69 per cent over the last 10 years – and may grow from 900,000 to 1.2 million by 2010. Within the Toronto Central LHIN, approximately 1 in 10 adults are living with diabetes, representing over 90,000 people.

The Ontario Diabetes Strategy was created to improve diabetes prevention and assist the growing population of people living with diabetes. Given the Toronto Central LHIN's unique urban, multi-cultural setting, combined with a high prevalence of diabetes and at-risk populations, it has been selected as one of three LHINs to participate in Ontario's Diabetes Strategy.

The Strategy encompasses prevention, promotion of healthier living and an emphasis on improving supports and services for people living with diabetes. The Toronto Central LHIN is working with a variety of partners within health care and the Ministry of Health and Long-Term Care. In particular, the Ministry of Health Promotion and Toronto Public Health play a significant role with the goal of promoting and reducing the incidence of diabetes.

COMMUNITY ENGAGEMENT

In order to understand diabetes care from the perspectives of people living with diabetes, the Toronto Central LHIN engaged people living with diabetes with a particular focus on marginalized individuals who face barriers to health and social services; neighbourhoods with higher rates of diabetes and fewer services/resources; higher populations of new immigrants; and lower income households.

During February and March of 2009, we engaged people in two ways: 1) community-based focus sessions; and 2) a larger public forum. The focus sessions took place at community-based agencies, in high needs/high risk neighbourhoods, where people living with diabetes already gather for diabetes related education programs.

Our objectives for the community engagement included:

- understanding the challenges faced by people living with diabetes
- determining the current gaps in diabetes care
- identifying ways to improve diabetes care
- helping people better manage their diabetes
- building awareness about Ontario's Diabetes Strategy

Focus Sessions

LHIN facilitators met with people living with diabetes in six separate focus sessions. This engagement approach provided an intimate environment for people living with diabetes to talk about the barriers they face managing their diabetes and what supports and services would make a positive difference. Each focus session averaged between 5 – 40 people who ranged in age from 25 – 75 years, representing a number of diverse communities including but not limited to: South Asian; Vietnamese; Caribbean; Spanish speakers; seniors and individuals accessing the Ontario Disability Supports Program.

Focus Session Questions

- **Where do you go for your diabetes care? What does that care look like?**
- **What health programs and services do you access? What services are missing?**
- **What are the main challenges you face, as someone living with diabetes?**
- **What can be done to help you better manage your diabetes?**

Focus Session Sites

The six sites were: The West Toronto Diabetes Education Centre; South Riverdale Community Health Centre; Flemingdon Health Centre; York Community Services; New Heights Community Health Centre; and East End Community Health Centre.

Public Forum

Toronto Central LHIN hosted a public forum on March 10th, 2009, for people living with diabetes. Flyers were distributed widely through various networks, including: Toronto Central LHIN's nearly 200 health service providers who, in turn, fanned them out to many community and ethno-cultural groups; the Canadian Diabetes Association; Toronto Public Health and the various diabetes education centres throughout the LHIN.

Approximately 150 people attended the forum and participated in small group discussions of two questions:

- What challenges do you face as a person living with diabetes?
- What can be done to improve diabetes care?

WHAT WE HEARD: CHALLENGES AND OPPORTUNITIES

Challenges Faced by People Living With Diabetes

Common themes emerged from the focus sessions and the public forum about challenges faced by people living with diabetes. Here is what we heard:

Challenges with Access to Care:

- Diabetes Education Programs may not have all the health service providers in one location (e.g. podiatrists, nurses, dietitians)
- Referrals to specialists may take too long (e.g. endocrinologists, ophthalmologists)
- There are limited services for diverse ethno-cultural and linguistic communities
- Medical supplies necessary to manage diabetes are costly (e.g. strips, needles, glucometers)
- Transportation to Diabetes Education Programs may be unavailable or costly
- Lack of access to diabetes home-care services after discharge from the hospital

Challenges in Care Coordination:

- Services are not centralized, or located in one place, making it difficult to receive all of the necessary care in a coordinated way
- Coordinated care may be received ‘too late’ and after diabetes is already uncontrolled
- Not enough information sharing between health service providers

Challenges in Managing Diabetes:

- Lack of access to healthy foods and affordable exercise facilities
- Not enough culturally-specific dietary and nutrition information
- Limited number of sessions for diabetes education and lack of follow-up support
- Diabetes management devices are not user-friendly (e.g. patients struggle with using a glucometer that requires pricking finger)
- Language barriers on food labels, education material & when communicating
- Programs patients rely on sometimes get cancelled due to funding (e.g. community kitchens, community gardens, yoga classes)

Challenges in Finding Information:

- Information may be conflicting or inconsistent (e.g. multiple provider care plans; advice on insulin vs. oral medications)
- No centralized resource for comprehensive and accurate diabetes information

Supports That Would Make a Difference

Participants identified ways to improve diabetes care and help them better manage their diabetes. As with the challenges, many of the recommended improvements go beyond health care services and the mandate of the LHIN.

Improving Access to Care:

- More coverage for drugs and medical supplies
- “One-stop shop” for services would minimize the travel and time burden for people living with diabetes
- Language and cultural considerations for diverse communities

Improving Care Coordination:

- Case managers/care coordinators who can help people living with diabetes navigate the health system and coach/educate patients
- Support to help motivate individuals and help them deal with the heavy burden of diabetes (e.g. more mental health support)
- Comprehensive team-based care available at the Diabetes Education Programs
- Better promotion of local, accessible resources (e.g. foot care clinics, community kitchens, walking groups, dietitian hotline)
- An organized, clear program and care plan once a person is diagnosed (i.e. communicated by physician)

Improving Self-Management:

- Affordable access to healthy food and exercise options (e.g. gyms, recreation centres; supermarkets with “diabetes” section)
- More local activities to promote healthy living (e.g. community gardens, walking groups)

Improving Access to Information:

- One recognized, accountable resource for all educational material
- A web tool used as a personalized program for individuals with diabetes
- A “help line” for diabetes-related questions
- Different ways to receive information (e.g. using electronic media, email lists, group sessions, one-on-one sessions, drop-in)

NEXT STEPS

At the Toronto Central LHIN, we are committed to improving coordination and access to care through the Diabetes Strategy. Recommendations for improving diabetes care in the Toronto Central LHIN comes from the input gathered from people living with diabetes and will be put forward to the Ministry of Health and Long-Term Care, along with data collected from statistical analysis, surveys, research, as well as consultations with health service providers.

As the Ministry moves forward to roll out the Diabetes Strategy, we will continue to engage people with diabetes. A key focus of this engagement will be to reach people living with diabetes, who are not connected to team based care, so that their perspectives are included in how care is delivered in the Toronto Central LHIN.

ADDITIONAL INFORMATION

For more information on the Ontario Diabetes Strategy, please visit the Ministry's website:

http://www.health.gov.on.ca/english/media/news_releases/archives/nr_08/jul/nr_20080722.html

The Toronto Central LHIN has posted slides from the March 10th diabetes forum, which can be viewed on our website at:

<http://www.torontocentrallhin.on.ca/Page.aspx?id=2122>

The Canadian Diabetes Association is full of valuable resources for people living with diabetes. Please find out more about their various activities by visiting:

<http://www.diabetes.ca/>

Dr. Ian Blumer is a diabetes specialist in the greater Toronto area and speaker at the March 10th diabetes forum. He has written several books including "Diabetes for Canadians for Dummies." Dr. Blumer's website is:

<http://www.ourdiabetes.com/>

The Toronto Public Health website is full of information about the prevention of diabetes. http://www.toronto.ca/health/pdf/nm_diabetes.pdf