Provincial Council for Maternal and Child Health

building a brighter future

Ontario Paediatric Diabetes Network

Mental Health and Psychosocial Working Group Recommendations Report

February 2016

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Executive Summary

Seventy percent of all mental health issues and addictions emerge in childhood and adolescence (Ministry of Children and Youth Services, 2012) and in the province of Ontario, 15 to 20 percent of children and youth have a mental health need (Ministry of Children and Youth Services, 2006; Minister's Advisory Group on the 10-year Mental health and Addictions Strategy, 2010; Ministry of Children and Youth Services, 2012). For children and youth living with type 1 diabetes, the prevalence of mental health and psychological conditions increases to one third (Hood, Huestis, Maher, Butler, Volkening, & Laffel, 2006), with specific risk for anxiety, depression, and eating disorders (Hood, Huestis, Maher, Butler, Volkening, & Laffel, 2006; Lawrence, et al., 2006; Fogel & Weissberg-Benchell, 2010; Colton P. A., Olmsted, Daneman, & Rodin, 2013). Children and youth with diabetes who are also afflicted by a mental health condition or lacking psychosocial supports are at an increased risk for poor glycemic control, which can lead to more rapid onset and progression of both short-term and long-term health complications (Diabetes Control and Complications Trial Research Group, 1995; Fowler, 2008; Diabetes Control and Complications Trial Research Group, 1994; Reynolds & Helgeson, 2011).

To ensure optimal diabetes management, children and youth living with diabetes require the support of a multidisciplinary paediatric diabetes team including social workers and access to mental health clinicians, with an approach to treatment that incorporates an understanding of the impact of social and psychological factors on the management of diabetes in children and youth. While psychological support is acknowledged as an important area of care, it is uncommonly included as part of routine paediatric diabetes care due to either lack of resources or expertise (Skinner & Cameron, 2010). This lack of mental health and psychosocial supports for paediatric diabetes patients holds true in Ontario, where paediatric diabetes education programs have indicated that providing and accessing adequate mental health and psychosocial supports for their patients and families is a major challenge in the provision of optimal diabetes care.

The Ontario Paediatric Diabetes Network established the Mental Health and Psychosocial Working Group (MHP-WG) in December 2013 to effect change in the paediatric diabetes landscape by addressing the challenges and discrepancies associated with access to mental health and psychosocial care for paediatric diabetes patients. The MHP-WG was tasked with developing a comprehensive set of recommendations regarding a provincial approach for paediatric diabetes programs to improve access and coordination of mental health and psychosocial services for youth living with diabetes and their families. The intent of this set of recommendations is to improve access and cultivate a more streamlined process for paediatric diabetes patients seeking mental health and psychosocial supports across the province of Ontario. Access to mental health and psychosocial care is limited across the province for all children and youth seeking care, not just for those living with diabetes. The daily management of diabetes poses unique challenges for children, youth and their families and can put patients at even greater risk of developing significant mental health conditions, which can impact their wellbeing and physical health, and can result in considerable costs to the healthcare system. By identifying specific needs and enabling the streamlining of mental health services for the pediatric diabetes population, the recommendations put forth in this report focus on an approach that aligns with other provincial initiatives aiming to improve mental health for children and youth. Furthermore, this report explores the impact that mental health and psychosocial conditions have in the broader system on the long-term outcomes of the population they address and on

how to leverage resources that currently exist within the Ontario healthcare system. The MHP-WG has put forth the following recommendations to be implemented across the province:

1. **Alignment with Provincial Programs and Services:** Where possible, the provision of care for paediatric diabetes patients with mental health or psychological conditions should complement and align with the programs and services that are part of Ontario's Comprehensive Mental Health and Addictions Strategy, the Moving on Mental Health Action Plan, and other relevant provincial strategies.

   Paediatric diabetes teams should be made aware of the programs and services supported by the Ministry of Children and Youth Services, Ministry of Health and Long-Term Care, Local Health Integration Networks, Paediatric Diabetes Network, and community partners and how to access them. Such programs and services include:
   - Tele-psychiatry
   - Community youth suicide prevention efforts
   - The School Mental Health ASSIST program

2. **Enhancing Capacity and Access:** Paediatric diabetes teams should be involved in the identification and management of mental health and psychosocial conditions in paediatric diabetes patients. Recognizing this, all paediatric diabetes teams should place a focus on the following:
   A. Increasing the team's capacity to identify and manage mental health and psychosocial conditions:
      - Staff on every paediatric diabetes team should have the opportunity to participate in training to increase their capacity to identify and manage mental health conditions in diabetes patients, and existing staff with this expertise (e.g., social workers, psychologists) should provide this support within their scope of practice whenever possible.
   B. Improving the coordination of access to child and youth mental health services:
      - Linkages between paediatric diabetes teams and child and youth mental health clinicians should be established and improved for consultation and/or shared care when necessary. This may include an in-person/on-site visit with a mental health clinician, or a community and/or video conference consultation.

3. **Improving Communication and Collaboration:** Effective communication and collaborative opportunities, such as shared care and information sharing where appropriate, should be facilitated between paediatric diabetes teams and mental health agencies in the community, as well as between patients and their healthcare providers. Tools for consideration include:
   - A memorandum of understanding (MOU) between the paediatric diabetes teams and child and youth mental health agencies.
   - For patients and families, the development and implementation of a diabetes health passport. This passport should include relevant mental health, psychosocial, and diabetes-related medical information for patients accessing services to share with external mental health clinicians.

4. **Use of Assessment and Screening Tools:** A standardized approach to the assessment and screening of psychosocial concerns and mental health concerns in paediatric diabetes care should be developed. As part of this approach, all paediatric diabetes patients in Ontario should receive routine assessment and screening based upon a standardized schedule.

5. **Access to Information:** An online resource centre should be established that provides diabetes-related mental health and psychosocial tools, templates and educational resources for healthcare providers, patients and their families.

6. **Increase Awareness in the School System:** Efforts should be made to increase the knowledge and understanding in local school systems of the various aspects and challenges of living with diabetes. The resources that have been compiled by paediatric diabetes care providers and reviewed by the members of the Mental Health & Psychosocial Working Group will be shared provincially.

7. **Revisit Diabetes Team Funding:** The 2010 Staff Funding Benchmark Review should be updated to accurately reflect 2015 patient volumes and case complexity, and dialogue should be opened with the MOHLTC toward the implementation of increased paediatric diabetes team FTEs to support the achievement of appropriate standards of care.

Prioritization of these recommendations, along with planning for their implementation and evaluation, will be forthcoming.

Acronyms and Glossary

Term	Definition
HbA1c	Glycated hemoglobin
CAMH	Centre for Addiction and Mental Health
CDA	Canadian Diabetes Association
CPEG	Canadian Pediatric Endocrine Group
CPS	Canadian Paediatric Society
Council	See PCMCH
FTEs	Full-time employees
ISPAD	International Society for Pediatric and Adolescent Diabetes
LHIN	Local Health Integration Network
MCYS	Ministry of Child and Youth Services
MEDU	Ministry of Education
MHP-WG	Mental Health and Psychosocial Working Group
MOHLTC	Ministry of Health and Long Term Care
MOU	Memorandum of Understanding
MTCU	Ministry of Training, Colleges and Universities
NOPDP	Network of Ontario Paediatric Diabetes Programs
OTN	Ontario Telemedicine Network
PCMCH	Provincial Council for Maternal and Child Health
PDEP	Paediatric Diabetes Education Program *For the purposes of this report, PDEP is interchangeable with paediatric diabetes team. A PDEP is comprised of a multidisciplinary core team of, at a minimum, a registered nurse, a registered dietitian, and a registered social worker, who work closely with paediatricians, and/or paediatric endocrinologists, and/or primary care providers to provide comprehensive care to children and youth living with diabetes.*
PDN	Paediatric Diabetes Network
The Service	Ontario's Tele-Mental Health Service

Background

Mental health issues can manifest in a range of symptoms and impairments that affect an individual's productivity and activities of daily living (Ministry of Children and Youth Services, 2006; Minister's Advisory Group on the 10-year Mental health and Addictions Strategy, 2010; Ministry of Children and Youth Services, 2012). Seventy percent of all mental health issues and addictions emerge in childhood and adolescence (Ministry of Children and Youth Services, 2012) and in the province of Ontario, 15 to 20 percent of children and youth have a mental health need (Ministry of Children and Youth Services, 2006; Minister's Advisory Group on the 10-year Mental health and Addictions Strategy, 2010; Ministry of Children and Youth Services, 2012). For children and youth living with type 1 diabetes, the prevalence of mental illness and psychological conditions increases to one third (Hood, Huestis, Maher, Butler, Volkening, & Laffel, 2006).

Type 1 diabetes is one of the most common chronic illnesses amongst children and youth (Reynolds & Helgeson, 2011). With the complexity of treatment, evolving technologies, and level of family involvement required for successful management, it is a demanding, multifaceted chronic disease in children and youth (Frank, 2005). It also has significant financial implications for patients, their families and the healthcare system, contributing to the overall cost of diabetes care in Ontario, which was estimated at $5.8 billion in 2014 (Canadian Diabetes Association, 2014). Children and youth living with diabetes are required to monitor their blood glucose levels multiple times per day and balance their dietary intake, medication, and physical activity levels. It is recommended that children and youth check their blood glucose levels at least four times a day, with more frequent monitoring oftentimes being optimal (Lawrence, Cummings, Pacaud, Lynk, & Metzger, 2015). Good metabolic control, and in turn successful diabetes management, depends on a multitude of factors including a healthy psychological environment and an intact support system. There is a substantial body of evidence illustrating that children and youth living with diabetes are at a significantly higher risk of developing mental health and psychological issues including anxiety, depression, disturbed eating behaviours and externalizing disorders (Hood, Huestis, Maher, Butler, Volkening, & Laffel, 2006; Lawrence, et al., 2006; Fogel & Weissberg-Benchell, 2010; Colton P. A., Olmsted, Daneman, & Rodin, 2013). For instance, a number of studies have shown that eating disorders and milder disturbed eating behaviours are considerably more prevalent in female youths and adolescents with type 1 diabetes as compared to their non-diabetic peers (Colton P. , Olmsted, Daneman, Rydall, & Rodin, 2004; Jones, Lawson, Daneman, Olmsted, & Rodin, 2000).

Studies have shown that the presence of mental illness, often occurring in combination with complex psychosocial conditions, can be associated with adherence problems and can negatively impact metabolic control, diabetes management and overall quality of life (Hassan, Loar, Anderson, & Heptulla, 2006; McDonnell, Northam, Donath, Werther, & Cameron, 2007; Herzer & Hood, 2009; Colton P. A., Olmsted, Daneman, & Rodin, 2013). Children afflicted by mental illness and/or lacking psychosocial supports are at an increased risk for poor glycemic control, which can lead to more rapid onset and progression of both

short-term (e.g. diabetic ketoacidosis requiring inpatient admission) and long-term health complications, such as circulatory problems, kidney failure, amputation, blindness or stroke (Diabetes Control and Complications Trial Research Group, 1995; Fowler, 2008; Diabetes Control and Complications Trial Research Group, 1994; Reynolds & Helgeson, 2011). Furthermore, adherence to medical treatment regimens is greatly impacted by the emotional wellbeing of a child or youth with diabetes and the overall wellbeing of others in their social network, particularly their parents or caregivers. Research has shown that family conflict can be associated with poor glycemic control and diminished adherence to treatment regimens (Delamater, de Wit, McDarby, Malik, & Acerini, 2014). A parent's or caregiver's distress can have significant implications on a child's diabetes management and the development of mental health and psychological issues (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, Wherrett, Huot, Mitchell & Pacaud, 2013). For instance, studies have demonstrated that a mother's anxiety and depression is associated with poor glycemic control in youth and diminished motivation in adolescents (Cameron, Young, & Wiebe, 2007).

To ensure optimal diabetes management, children and youth require the support of a multidisciplinary paediatric diabetes team including social workers and access to mental health specialists, such as psychologists, with an approach to treatment that incorporates an understanding of the impact of social and psychological factors on the management of diabetes in youth. While psychological support is acknowledged as an important area of care, it is uncommonly included as part of routine paediatric diabetes care due to either lack of resources or expertise (Skinner & Cameron, 2010). De Wit, Pulgaron, Pattino-Fernandez and Delamater (2014) recently conducted a study examining whether the clinical practice guidelines for psychosocial care in children and youth with type 1 diabetes, developed by the International Society for Pediatric and Adolescent Diabetes (ISPAD), were being met. Paediatric diabetes teams from 47 countries participated in this study (de Wit, Pulgaron, Pattino-Fernandez, & Delamater, 2014). The authors found that although 95% of the paediatric diabetes teams discussed psychosocial difficulties associated with the management of diabetes, almost 30% reported that they do not have access to mental health practitioners and 44% reported that they do not have a mental health practitioner as part of their interdisciplinary team (de Wit, Pulgaron, Pattino-Fernandez, & Delamater, 2014). This lack of mental health and psychosocial supports for paediatric diabetes patients holds true in Ontario, where the majority of paediatric diabetes education programs (PDEPs) have no access to a psychologist and only limited access to social work support. The PDEPs across the province have indicated that providing and accessing adequate mental health and psychosocial supports for their patients and families is a major challenge in the provision of optimal diabetes care.

Notwithstanding the fiscal limitations and resource constraints within the current healthcare system, it is important to identify specific needs and develop an approach that streamlines mental health services for the paediatric diabetes population, improves access, and aligns with other provincial initiatives aiming to improve mental health care for children and youth.

Mental Health and Psychosocial Working Group

The Mental Health and Psychosocial Working Group (MHP-WG) is a working group of the Ontario Paediatric Diabetes Network of the Provincial Council for Maternal and Child Health (PCMCH/Council).

PCMCH is an organization whose scope is primary, secondary, tertiary and quaternary maternal, newborn, child and youth health services, delivered in both community and hospitals settings, and includes responding to the needs of disadvantaged communities across Ontario. The Council's work reflects the importance of relationships and interfaces among providers and organizations across the continuum of care.

The Council's vision is: The Best Possible Beginnings for Lifelong Health
Its mission is to:

- **Be the provincial forum** in which clinical and administrative leaders in maternal and child health can identify patterns and issues of importance in health and health care delivery for system support and advice.
- **Improve the delivery** of maternal child health care services by building provincial consensus regarding standards of care, leading practices and priorities for system improvement.
- **Provide leadership and support** to Ontario's maternal and child health care providers, planners and stewards in order to maximize the efficiency and effectiveness of health system performance.
- **Mobilize information and expertise** to optimize care and contribute to a high-performing system therefore improving the lives of individual mothers and children, providers and stewards of the system.

The Ontario Paediatric Diabetes Network (PDN) is a collaborative network comprised of the thirty-five specialized paediatric diabetes education programs (PDEPs) located in communities across the province of Ontario. The goal of this network is to ensure the best possible health outcomes for children and youth affected by diabetes across the province. To this end, PCMCH oversees the coordination of the PDN by fostering system improvement, providing opportunities for professional development, promoting linkages between the PDEPs, assisting with the development and dissemination of resources and guidelines, promoting consistency in standards of practice, and providing individual program support. The MHP-WG was convened as a working group of the PDN in December 2013 and committed to:

1. The completion of a report detailing a comprehensive set of evidence-informed recommendations regarding a provincial approach for paediatric diabetes programs to improve access and coordination of mental health and psychosocial services for youth living with diabetes and their families.
2. The development of tools and knowledge transfer mechanisms to support the implementation of these recommendations by PDEPs, patients and families, hospital and community mental health providers, Local Health Integration Networks (LHINs), and the Ministry of Health and Long-Term Care (MOHLTC), as appropriate.

Refer to Appendix 1 for the MHP-WG terms of reference.

The membership of the MHP-WG covered different geographical regions across Ontario and is comprised of representation from various paediatric and adult diabetes stakeholder groups including social workers, psychologists, psychiatrists, a senior policy advisor and LHIN representation. Efforts were made to ensure representation from across the province, including both tertiary and community hospitals and healthcare centres. Refer to Appendix 2 for the MHP-WG membership.

The recommendations put forth by the MHP-WG were based upon evidence, a series of environmental scans and expert consultations. The development of these recommendations was achieved over a series of meetings that were held via teleconference, in addition to one in-person meeting that took place in September 2014. Based on the preliminary MHP-WG meetings, the recommendations were partitioned into the three themes and the following subgroups convened to address each theme:

- Capacity and Access Subgroup
- Assessment and Screening Subgroup
- Education and Resources Subgroup

To foster collaboration and ensure alignment across the vast provincial healthcare system, the MHP-WG referred to the PCMCH Emergency Department Clinical Pathways Report as a framework for developing this set of recommendations. The MHP-WG tailored, refined and expanded upon these recommendations in order to address the unique characteristics and needs of youth living with diabetes, as well as the structure of diabetes care across the province.

Recommendation 1: Alignment with Provincial Programs and Services

Where possible, the provision of care for paediatric diabetes patients with mental health or psychological conditions should complement and align with the programs and services that are part of Ontario's Comprehensive Mental Health and Addictions Strategy, the Moving on Mental Health Action Plan, and other relevant provincial strategies.

Paediatric diabetes teams should be made aware of the programs and services supported by the Ministry of Children and Youth Services, Ministry of Health and Long-Term Care, Local Health Integration Networks, Paediatric Diabetes Network, and community partners and how to access them. Such programs and services include:

- **Tele-psychiatry**
- **Community youth suicide prevention efforts**
- **The School Mental Health ASSIST program**

Rationale

Mental health and psychosocial care for paediatric diabetes patients is just one component of the broader, multifaceted system of mental health services in Ontario. It is clear that collaborative efforts need to be made amongst all stakeholders to ensure that there is alignment across the province, linkages across sectors and continued support of initiatives that impact children and youth with mental illness or psychological conditions. The purpose of this recommendation is to raise awareness about and encourage alignment with the provincial strategies and initiatives underway, so that services for children and youth with diabetes can be optimized. This recommendation also recognizes the importance of ensuring that there is ongoing dialogue among stakeholders across the province to foster such that efforts are not duplicated and initiatives are well-coordinated and target the needs of the most vulnerable children and youth including those within the diabetes community.

The prevalence of mental health conditions in children and youth, along with the challenges associated with addressing their needs, have been acknowledged as a high priority for the healthcare system in Ontario. The responsibility for addressing these challenges is being shared by a number of stakeholders including the MOHLTC, the Ministry of Child and Youth Services (MCYS), the Ministry of Education (MEDU) and the Ministry of Training, Colleges and Universities (MTCU), LHINs, mental health agencies and healthcare providers. Each stakeholder group has a significant role to play when it comes to the oversight, delivery and integration of mental healthcare services in the healthcare landscape. There are a variety of provincial strategies and initiatives underway to address this area and enable improvements in the provincial healthcare system. One such strategy is the Government of Ontario's *Comprehensive Mental Health and Addictions Strategy, Open Minds, Healthy Minds*. This strategy was released in 2011 as a means to transform the mental health system in Ontario and enhance system coordination "through a clear mission, forward-thinking vision and long-term strategies for change" (Ontario Ministry of Health and Long-Term Care, 2011). The recommendations put forth by the MHP-WG are aligned with two of the overall goals of this strategy:

- Identifying mental health and addictions problems early for intervention
- Providing timely, high quality, integrated person-directed health and other human services

The first three years of this 10-year strategy focus on the mental health and well-being of children and youth. This part of the strategy is being implemented in partnership by the MOHLTC, MCYS, MEDUd and MTCU, and aims to fulfill a number of priorities, including: providing children, youth and families with fast access to high quality services and closing service gaps for vulnerable children and youth, children and youth at key transition points, and those in remote communities.

Within the first year of implementing the *Comprehensive Mental Health and Addictions Strategy*, a number of improvements were realized including the provision of mental health services to approximately 20,000 children and their families (Ministry of Children and Youth Services, 2012). To continue moving forward with the strategy, the MCYS developed the *Moving on Mental Health: A system that makes sense for children and youth* action plan. This three-year action plan aims to build upon the investments already made and create a system that supports children and youth with mental health conditions (Ministry of Children and Youth Services, 2012). The action plan also entails creating and supporting care pathways, defining core mental health services, establishing lead agencies in the communities, creating a new funding model and building a legislative and regulatory framework (Ministry of Children and Youth Services, 2012).

To further support the priorities of this strategy, the MOHLTC has engaged the Institute for Clinical Evaluative Sciences to develop a baseline scorecard for child and youth mental health in Ontario. This baseline scorecard report was released in March 2015 and includes both contextual and performance indicators that illustrate the system performance and current state of child and youth mental health and addictions care in Ontario (MHASEF Research Team, 2015). Some of the findings of the baseline scorecard report include: prevalence of mental health conditions varies by socioeconomic and geographic factors, prevalence of some mental health conditions have increased over time, and making targeted investments in mental health and addiction services were associated with improved access to care (MHASEF Research Team, 2015).

The Government of Ontario has also designated lead agencies as a means to strengthen the delivery of community-based mental health services (Ministry of Children and Youth Services, 2015). The lead agencies are responsible for the planning, funding, monitoring and evaluation of the child and youth mental health services in their areas (Ministry of Children and Youth Services, 2015). As of August 2015, the MCYS has designated twenty-eight healthcare organizations providing community-based child and youth health care as lead agencies (Ministry of Children and Youth Services, 2015). The Ontario government will be identifying thirty-three lead agencies (Ministry of Children and Youth Services, 2015). For a full list of the lead agencies, see Appendix 3.

Another provincial service is the Ontario *Tele-Mental Health Service* (The Service), which provides expanded access to specialized mental health services to children and youth in rural, remote and underserved communities across the province. MCYS funds The Service to deliver mental health services including psychiatric consultations, clinical assessments, recommendations for medication and treatment, program consultations, education and counselling (Ministry of Children and Youth Services, 2007; The Hospital for Sick Children, 2014). The Service consists of three "Hubs" – the Hospital for Sick Children through the *Telelink Mental Health Program* (Central Hub), the Children's Hospital of Eastern Ontario (Eastern Hub) and the Child and Parent Resource Institute (Western Hub) – that use videoconferencing to provide these specialized mental health services. Videoconferencing helps to connect children and youth, who are already receiving mental health services, to a specialist who can address their issues so that they can access the care they need as close to home as possible.

The Service is being provided in 35 rural, remote and underserved communities identified as having the greatest need for child and youth mental health services. It will help to provide culturally-appropriate services to First Nations, Métis, Inuit, urban Aboriginal, and francophone children, youth and their families. All publically-funded mental health clinicians are able to refer children and youth to the Tele-Mental Health Service by contacting one of the six Tele-Mental Health Service coordination agencies.

In order to foster support, integration and efficiencies across the broader healthcare system, it is important to ensure that the efforts to improve coordination of and access to mental health services for children and youth with diabetes complement the provincial strategies, and leverage the initiatives that are underway. The recommendations put forth by the MHP-WG align well with other provincial initiatives and strategies since: diabetes adds a significant burden to patients and their families, particularly those with decreased socioeconomic status and other resource needs; children and youth with diabetes are at an increased risk of developing mental health conditions; and the mental health needs of children and youth with diabetes can be targeted specifically through coordinating access to care by the PDEPs and their community partners.

Recommendation 2: Enhancing Capacity and Access

Paediatric diabetes teams should be involved in the identification and management of mental health and psychosocial conditions in paediatric diabetes patients. Recognizing this, all paediatric diabetes teams should place a focus on the following:

A. Increasing the team's capacity to identify and manage mental health and psychosocial conditions:
- **Staff on every paediatric diabetes team should have the opportunity to participate in training to increase their capacity to identify and manage mental health conditions in diabetes patients, and existing staff with this expertise (e.g., social workers, psychologists) should provide this support within their scope of practice whenever possible.**

B. Improving the coordination of access to child and youth mental health services:
- **Linkages between paediatric diabetes teams and child and youth mental health clinicians should be established and improved for consultation and/or shared care when necessary. This may include an in-person/on-site visit with a mental health clinician, or a community and/or video conference consultation.**

Rationale

There are opportunities to build efficiencies within existing systems that can accompany the provincial initiatives to ensure that children and youth have access to appropriate mental healthcare and psychosocial services at the right time and in the right place. One such opportunity is within the paediatric diabetes teams across the province and is addressed in this two-part recommendation. This recommendation focuses on building capacity from within and improving the coordination of access to community-based mental health and psychosocial care when it is deemed necessary or beyond the scope of the PDEPs.

Due to the nature of diabetes management, PDEPs provide ongoing interdisciplinary care to children and youth with diabetes, typically over many years. In doing so, paediatric diabetes teams often form close, longstanding relationships with patients and their families. The members of the paediatric diabetes teams also acquire a multifaceted understanding of their patients' needs and the way diabetes management can affect a patient's day-to-day life, psychological state and overall wellbeing. Paediatric diabetes care providers are therefore uniquely positioned to be able to offer meaningful support to families who are coping with the challenges of paediatric diabetes management, and to both detect and intervene in potential mental health or psychosocial issues. Given these circumstances, members of paediatric diabetes teams should have the opportunity to acquire the skills and tools required in order to build their capacity to identify and manage mental health and psychosocial conditions. Building capacity in this way aligns with the goals of Ontario's *Comprehensive Mental Health and Addictions Strategy* as it would help to ensure that mental health conditions are identified early on and that paediatric diabetes patients receive mental health care that is congruent with the management of their diabetes. This portion of the recommendation is also consistent with the ISPAD recommendation, which states that members of the interdisciplinary diabetes care team should be trained in recognizing, identifying, providing information and counselling for psychosocial issues related to diabetes (Delamater, de Wit, McDarby, Malik, & Acerini, 2014). As part of building capacity, it is also important to recognize the potential and capacity that already exists within the PDEPs through the work of social workers and psychologists in particular to treat mental health conditions. These members of the paediatric diabetes

team bring a wealth of clinical expertise and skills, and can provide specialized mental health and psychosocial care to children and youth with diabetes.

There are provincial initiatives underway that can be leveraged to build capacity within the PDEPs, including *Ontario's TeleMental Health Service* (as described in Recommendation 1), the *Medical Psychiatry Alliance* and the *Working with Children and Youth with Complex Mental Health Needs: An Integrated Training Project*. The *Medical Psychiatry Alliance* was launched in January 2014 by the Ontario government in partnership with the Centre for Addiction and Mental Health (CAMH), the Hospital for Sick Children, Trillium Health Partners, the University of Toronto and a private donor (Ministry of Health and Long-Term Care, 2014). This collaborative, six-year initiative aims to support Ontarians living with both physical and mental health conditions (Ministry of Health and Long-Term Care, 2014). The main goals of this initiative are to ensure that patients receive treatment for their physical and mental health conditions simultaneously and that tools are developed to ensure that patients are properly diagnosed (Ministry of Health and Long-Term Care, 2014). The *Working with Children and Youth with Complex Mental Health Needs: An Integrated Training Project* was a one-year initiative aligned with the *Moving on Mental Health* action plan (Canadian Mental Health Association Ontario, 2015). It was funded by the MCYS and conducted by the Ontario Branch of the Canadian Mental Health Association with the goal of helping care providers enhance their skills in key areas including Family/Caregiver Skills Building and Support, Targeted Prevention, and practicing within a health equity lens (Canadian Mental Health Association Ontario, 2015). This initiative produced a number of training resources that remain available online to direct healthcare providers (Canadian Mental Health Association Ontario, 2015).

The second portion of this recommendation addresses situations in which a patient's mental health or psychosocial needs move beyond the scope of practice or resources (e.g. staffing) of the PDEPs. In these circumstances, PDEPs should refer the patient to a clinician within their community who has expertise in child and youth mental health care and availability to provide services. This portion of the recommendation aligns with the clinical practice guidelines released by the Canadian Diabetes Association in 2013, which indicate that children and youth with diabetes should be referred to an expert in mental health and psychosocial conditions for intervention when required (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, Wherrett, Huot, Mitchell & Pacaud, 2013). Examples of circumstances in which such a referral may be needed include when a parent or caregiver has mental health issues of their own and when consultation for treatment via psychiatric medication is needed. PDEPs should establish linkages, referral pathways, and relationships with mental health clinicians in the community to ensure that patients and their families are able to access mental health services as required. Efforts to coordinate access, establish linkages and equip paediatric diabetes teams, patients and families with information on the services available in their community should align with the provincial strategies and leverage initiatives being implemented across Ontario, such as Ontario's Tele-Mental Health Service (as described in Recommendation 1).

Helpful Resources

There is a variety of online resources that can help care providers, patients and families enhance their knowledge of the mental health services available in their communities. For instance, the government of Ontario has developed the Open Data Catalogue for Child and Youth Mental Health Services. This is a webpage that houses a list of publicly funded child and youth mental health agencies, along with details

on the services offered through community agencies. For more information about this resource, including the online link to this resource, see Appendix 4. The government of Ontario has also created Health Care Options, which is an online portal that contains centralized information on a number of different health care services available across the province. The purpose of this portal is to help Ontarians learn about the health care services that are offered in their communities, where they are located and how to access them. An Ontario Child and Youth Mental Health Directory is also being developed by the MCYS as part of Ontario's Comprehensive Mental Health and Addictions Strategy. This directory has been incorporated into the Health Care Options portal. For more information about Health Care Options, see Appendix 5. Lastly, Children's Mental Health Ontario (CMHO) has developed an online directory of 89 accredited children's mental health agencies across Ontario. This directory includes details on each agency's contact information, the services they provide, the conditions they treat, and their locations. For more information about this resource, see Appendix 6.

In 2012-13, the Ontario Centre of Excellence for Child and Youth Mental Health (the Centre) assumed responsibility for the coordination of provincial education for Ontario's Tele-Mental Health Service. The Centre works closely with partners to identify opportunities to provide system-level input and guidance, while jointly developing collaborative and consistent approaches to addressing common challenges. Facilitating knowledge mobilization among agencies, service areas and sectors are in the Centre's core areas of expertise: evaluation, implementation, performance measurement, youth and family engagement.

The Tele-Mental Health Service provincial education program provides child and youth mental health clinicians with live and archived learning opportunities using the Ontario Telemedicine Network (OTN) videoconference and webcasting technology. This contributes to the Tele-Mental Health Service's mandate of helping local mental health clinicians provide the best possible service to children and youth in their community. In collaboration with the three Hubs of Ontario's Tele-Mental Health Service – the Hospital for Sick Children, the Children's Hospital of Eastern Ontario and the Child and Parent Resource Institute – the Centre delivers timely and relevant learning events to agencies across the province. The archived videos of the provincial education program can be accessed via the Centre's resource hub (http://www.excellenceforchildandyouth.ca/resource-hub/online-learning-events/tele-mental-health).

In future, the MHP-WG concluded that it would be helpful to develop a regional listing of child and youth mental health providers who have expertise or experience in providing care to diabetes patients. This resource would allow paediatric diabetes teams to make more targeted referrals to mental health services.

Recommendation 3: Improving Communication and Collaboration

Effective communication and collaborative opportunities, such as shared care and information sharing where appropriate, should be facilitated between paediatric diabetes teams and mental health agencies in the community, as well as between patients and their healthcare providers. Tools for consideration include:

- **A memorandum of understanding (MOU) between the paediatric diabetes teams and child and youth mental health agencies.**
- **For patients and families, the development and implementation of a diabetes health passport. This passport should include relevant mental health, psychosocial, and diabetes-related medical information for patients accessing services to share with external mental health clinicians.**

Rationale

Paediatric diabetes patients and providers are currently faced with a number of challenges when trying to access mental health and psychosocial care. For instance, when referring a patient to a mental health clinician in the community, there is no standardized tool for PDEPS to share pertinent patient information with the mental health clinician. For many patients and families, this information is shared with their paediatric diabetes care providers, who, in providing ongoing, regular care to children and youth with diabetes, PDEPs gain a comprehensive understanding of a patient's medical, mental health and psychosocial needs. What's more, there are no formalized agreements or consistent, formalized means of communication between the PDEPs and the child and youth mental health clinicians in the community. These obstacles, which stem from complexity of care and fragmentation of the healthcare system, compel the need for additional attention to be paid to ensure that those who require these services are able to access them in a timely, responsive and appropriate manner. To address this need and mitigate these obstacles, the MHP-WG recommends the implementation of efforts and tools to enhance communication, collaboration and integration amongst all parties involved in the delivery of mental health services for children and youth with diabetes. These parties include patients, families, paediatric diabetes care providers, mental health clinicians, mental health agencies. Fostering ongoing dialogue between the paediatric diabetes care providers and the child and youth mental health clinicians will help to ensure that patients receive care that is tailored to their needs, that pertinent medical, mental health and psychosocial information is shared with the appropriate healthcare providers, and that, ultimately, there is seamless integration between the mental health and psychosocial care provided by the PDEPs and the community mental health agencies.

Helpful Resources

To address the need to enhance communication and collaboration amongst paediatric diabetes care providers and child and youth mental health agencies, the MHP-WG has created a MOU template. If used, this MOU should be agreed upon by all parties involved and entail the following key components:

- A statement describing the purpose of the MOU
- Governing principles agreed to by all parties involved regarding the partnership and provision of care

- Details regarding the parties to the MOU
- A referral process to improve access to specialty mental health services for paediatric diabetes patients
- Details on an agreed upon mechanism for communication of patient information
- An arrangement for collaborative care of complex patients
- Clarity regarding roles of the paediatric diabetes and mental health providers in managing the patient
- Information sharing and privacy details
- Details on how the MOU will be governed and maintained

The template developed is based upon the memorandum of agreement that was created for the purposes of the PCMCH Emergency Department Clinical Pathways Report. This is an optional tool that can be tailored to meet the specific resources and needs for each community. However if it is used, the MHP-WG recommends that each community have one common MOU to ensure consistency of clinical practices and service delivery.

Memorandum of Understanding for Managing Mental Health Conditions in Children and Youth with Diabetes (See Appendix 7)

To find a tool that would enhance two-way communication between patients and their healthcare providers, the Capacity and Access Subgroup reviewed several standardized referral tools. The Subgroup selected the MyHealth Passport for Diabetes, developed by the Good 2 Go Transition Program at the Hospital for Sick Children in Ontario as the foundation for this diabetes health passport. The MyHealth Passport is intended for patients as a quick snapshot of their information to carry with them as they transition to adult care (The Hospital for Sick Children). The passport itself is a wallet-sized card that lists an individual's health related information including medical conditions, past treatments and medical procedures, medications, allergies (The Hospital for Sick Children). To create their personalized MyHealth Passport, patients can visit the Hospital for Sick Children's website and complete the online template, then have it printed out to keep with them. In recommending this tool, the Subgroup adapted the MyHealth Passport template for diabetes to capture information about the patient's mental health conditions and/or psychosocial needs that would be relevant for both the patient and the mental health clinicians. Although the original MyHealth Passport is designed for transition to adult care, the revised diabetes passport can be used for children and youth at any age to facilitate communication between diabetes teams and community-based partners. The revised diabetes passport is a paper-based tool that is intended as a guide for patients and their families to share pertinent information with their healthcare providers. The Subgroup suggests that the paediatric diabetes team uses their discretion to determine whether the patient should take responsibility for sharing the passport with the mental health clinician, or whether the PDEP should assist in sharing the passport as part of their referral.

Revised MyHealth Passport – Diabetes (See Appendix 8)

Recommendation 4: Use of Assessment and Screening Tools

A standardized approach to the assessment and screening of psychosocial concerns and mental health concerns in paediatric diabetes care should be developed. As part of this approach, all paediatric diabetes patients in Ontario should receive routine assessment and screening based upon a standardized schedule.

Rationale

Routine assessment of and screening for mental health conditions and psychosocial concerns has received recognition internationally and nationally as an integral part of optimal paediatric diabetes care. The assessment of mental health and psychosocial needs is a complex process that relies on effective communication and relationships amongst patients, families and paediatric diabetes care providers, as well as knowledge of potential problem areas and resources. According to the recommendations put forth by the International Society for Pediatric and Adolescent Diabetes (ISPAD), psychosocial support should entail regular assessments, screening and the provision of effective interventions, and not just referral to mental health services (Delamater, de Wit, McDarby, Malik, & Acerini, 2014). The clinical practices guidelines developed by the Canadian Diabetes Association (CDA) are consistent with this recommendation, suggesting regular screening for mental health and psychosocial conditions for children and youth with diabetes and their caregivers (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, Wherrett, Huot, Mitchell & Pacaud, 2013). ISPAD also recommends that the interdisciplinary paediatric diabetes teams conduct regular assessments pertaining to general and diabetes-related family functioning (Delamater, de Wit, McDarby, Malik, & Acerini, 2014). The purpose of this recommendation is to emphasize the need for mental health and psychosocial screening and assessment of all paediatric diabetes patients and to begin establishing a standardized approach to such screening and assessment. This approach would assist in the development of targeted interventions to address mental health needs. It would also facilitate comparisons of needs and interventions within and between Ontario PDEPs and other parts of the world. In acknowledging the important role of regular assessments and screening and in alignment with the recommendations put forth by ISPAD and the CDA, the MHP-WG recommends that children and youth and/or their caregivers be screened (by the team's mental health provider whenever possible) to assess the risk of, and treatment needs for, mental health and psychosocial issues at the following key points in time:

Recommended Schedule for Screening and Assessment of Mental Health and Psychosocial Conditions:
1. Initial screening to identify any mental health conditions or psychosocial concerns by the team's mental health provider as close to the time of diagnosis as possible.
2. At a minimum, on an annual basis thereafter, with consideration of the patient's age, developmental stage, individual traits and family characteristics.
3. At times of individual need, such as in response to emerging concerns, symptoms, or perceived risk factors during clinic visits.

Helpful Resources

The MHP-WG recognizes that paediatric diabetes teams currently consider psychosocial and mental health needs of their patients, gathering information through a range of contacts between patients and members of the diabetes team. In order to facilitate comprehensive screening of psychosocial concerns

and mental health conditions, the Assessment and Screening Subgroup of the MHP-WG has drafted a general "triage" tool, consisting of key issues, with corresponding sample questions to help elicit information on these issues (see Appendix 9). This tool is to be used as a guide to assist teams with their face-to-face interactions with patients and their families in screening for mental health conditions and psychosocial concerns. It is recommended that teams review this triage tool to ensure that their current practices for screening include these key areas.

While screening may occur through interactions between members of the paediatric diabetes team and their patients and families, the Assessment and Screening Subgroup recognized that the implementation of structured tools could assist in developing a standardized approach for screening and assessment of mental health and psychosocial conditions across PDEPs. To that end, the Subgroup reviewed a number of general and diabetes-specific assessment tools. These tools ranged from general overviews of well-being, to specific aspects related to coping with diabetes, both on a personal level and within families. To facilitate the development of standardized screening for mental health conditions and psychosocial concerns on an ongoing basis, the Subgroup recommends the tools for children, youth and parents developed and used by the DAWN MIND Youth Programme, an international pediatric diabetes research program. These tools include the DAWN MIND Youth Questionnaire (MY-Q), the World Health Organization 5-item (WHO 5) Well-Being Index and the Problem Areas in Diabetes Survey – Parent Revised Version (PAID-PR). The MY-Q has been designed by the DAWN MIND Youth Programme to assess diabetes-specific quality of life for children and adolescents aged 10-18, whereas the WHO-5 is used to detect depressive symptoms in both patients and parents, and has been validated in adolescents with Type 1 diabetes. The PAID-PR is intended to assess the parent's or caregiver's distress as it relates to their child's diabetes-related distress. For more information about these tools, see Appendix 10. These tools should be considered for implementation by pediatric diabetes teams and formally trialed by several PDEPs to determine utility and feasibility of incorporating them into routine paediatric diabetes care in Ontario settings. The Subgroup also recommends that the list of the tools it reviewed be made available to paediatric diabetes teams as part of the online resource centre that is described in Recommendation 5.

Recommendation 5: Access to Information

An online resource centre should be established that provides diabetes-related mental health and psychosocial tools, templates and educational resources for healthcare providers, patients and their families.

Rationale

This recommendation addresses another strategy to build capacity and share knowledge amongst paediatric diabetes care providers and mental health clinicians in Ontario as well as with paediatric diabetes patients and their families. The intention of this online resource centre is to establish a web-based space where tools, templates, educational resources and information relevant to mental health and psychosocial care can be housed and easily accessed by paediatric diabetes care providers, mental health practitioners, patients and their families. This web-based space would house the resources recommended throughout this report along with other relevant resources such as archived video conferences, presentations, position statements and scientific articles related to paediatric diabetes care

and mental health and psychosocial support. The establishment of an online resource centre would help to enhance awareness and understanding of how diabetes can affect the mental health and psychosocial needs of children and youth and provide information for clinicians about evidence-based mental health treatments and management strategies for children, youth and families living with diabetes. Building such a web-based space will help to make information more easily accessible and reduce duplication of efforts across the province. This online resource centre should be easy to navigate, well-organized and populated with both the resources recommended throughout this report, those that had been reviewed but not selected to accompany a specific recommendation, and those from different jurisdictions. This online resource centre should be maintained by the PDN and housed on the PCMCH website, with links to relevant external websites.

Helpful Resources

The Education and Resources Subgroup compiled resources that were currently being used and determined which of these resources were appropriate to recommend to the paediatric diabetes teams across the province. Furthermore, the Subgroup assessed the gaps in knowledge and resources that are currently available. For a list of resources and websites recommended by the Subgroup to be included as part of the online resource centre, see Appendix 11.

There is also an opportunity for paediatric diabetes care providers and mental health clinicians to collaborate in order to develop an education module that addresses the intricacies of paediatric diabetes management and the challenges that can arise when caring for children and youth with both diabetes and mental health conditions or psychosocial concerns. Given the scope and the breadth of expertise that would be required to develop a formalized education module, the MHP-WG proposes that this would be a longer term priority and that its implementation should be considered at a later date. This module could be housed on and accessed through the online resource centre.

Recommendation 6: Increase Awareness in the School System

Efforts should be made to increase the knowledge and understanding in local school systems of the various aspects and challenges of living with diabetes. The resources that have been compiled by paediatric diabetes care providers and reviewed by the members of the Mental Health & Psychosocial Working Group will be shared provincially.

Rationale

The mental health and wellbeing of patients and families living with diabetes can be influenced by a multitude of factors, including social interactions with their peers, relationships with school personnel and the availability of school-based supports. In recent years, there has been elevated interest and rising concerns about how paediatric diabetes is being managed in schools and the inconsistencies in school-based support that exist across Canada (Lawrence, Cummings, Pacaud, Lynk, & Metzger, 2015). In 2014, the Canadian Paediatric Society (CPS) and the Canadian Pediatric Endocrine Group (CPEG) released a joint position statement that provides an overview of the issues and variation that currently exist and comprehensive policy recommendations regarding the kinds of school-based supports that should be in place to ensure the safety, health and dignity of students living with type 1 diabetes (Lawrence,

Cummings, Pacaud, Lynk, & Metzger, 2015). The CDA has also developed guidelines that outline the roles and responsibilities of students with diabetes, their families and their schools in the care and support of students living with diabetes.

This recommendation aligns with the CDA guidelines and CPS and CPEG joint position statement by focusing on ways to increase awareness and knowledge of paediatric diabetes in schools. The MHP-WG recognizes that the resources suggested represent but a first step in increasing awareness and understanding about living with diabetes in the school system, and further efforts will need to be undertaken to explore the important role that school systems and social networks play in the lives of children and youth living with diabetes and the support that might be offered there.

Helpful Resources

The Education and Resources Subgroup compiled and reviewed a series of tools related to the management of diabetes in schools that were currently being used across the province. Based on this review, the Subgroup selected the resources below to accompany this recommendation and to be used by PDEPs in working with their local school systems. In reviewing these materials, the Subgroup also assessed the current gaps in resources, discovering that although there were a variety of educational resources available to assist in educating school staff about diabetes in children and adolescents between the ages of 4-17, there was a lack of age-specific materials for children attending preschool or daycare. To help assess the quality of the following recommended resources, the Subgroup suggests that they be evaluated within a framework that considers different ages and stages of a child or adolescent. These stages include: preschool (Birth to 4 years); elementary (4 to 13 years); high school (14 to 17 years); and post-secondary (18+ years). The Subgroup has identified a number of resources from local, national and international organizations that could help families and schools to support children and youth with diabetes. The Subgroups suggests that this list of recommended resources be reviewed and revised as new materials are developed and become available.

Kids Diabetes Information Pack for Teachers (See Appendix 12)

- Developed by the International Diabetes Federation.
- This is a toolkit to inform teachers about diabetes in schools and is available at no cost.
- This was selected by the Subgroup as the preferred resource due to its level of detail and health literacy as well as the fact that it includes information about both type 1 and type 2 diabetes.

Guidelines for the Care of Students Living with Diabetes at School (See Appendix 13)

- Developed by the Canadian Diabetes Association.
- The Subgroup also preferred this resource as it clearly outlines the specific roles and responsibilities of the students, parents and school personnel.

Diabetes in Children and Teens: A Survival Guide (Appendix 14)

- Developed by the Trillium Health Centre in Ontario in 2008 to provide school staff with general information about type 1 diabetes
- This resource is compact in size, easy to read and has family-friendly design. It also has a companion video for teachers and support staff.

The Subgroup would also recommend the following resource, however there is a cost associated with its use:

The Guides for Successful Transition to College and University

- Developed by the Diabetes Hope Foundation.
- Available for $9.99 at http://diabeteshopefoundation.com/content/transition-resource-guide-0.
- Includes details about all colleges and universities in Ontario with specific information regarding health plans associated with the academic institutions as well as the closest adult diabetes education programs.
- These guides include an Ontario specific guide as well as a pan-Canadian guide.

Recommendation 7: Revisit Diabetes Team Funding

The 2010 Staff Funding Benchmark Review should be updated to accurately reflect 2015 patient volumes and case complexity, and dialogue should be opened with the MOHLTC toward the implementation of increased paediatric diabetes team FTEs to support the achievement of appropriate standards of care.

Rationale

Despite increasing patient volumes, increased time needed for patient education due to advancements in clinical technology, and calls for improved standards of care for paediatric diabetes – including specific targets for glycemic control and regular screening for psychosocial and mental health issues as outlined in the 2013 Canadian Diabetes Association Clinical Practice Guidelines – staffing benchmarks for PDEPs have remained unchanged since they were established over a decade ago. In 2010, the former Network of Ontario Paediatric Diabetes Programs (NOPDP) completed a Staff Funding Benchmark Review, which made recommendations for updated staffing ratios for the core members of paedatric diabetes teams – registered nurses, registered dietitians and social workers – across the province. This review revealed that PDEP staffing levels were insufficient in meeting the clinical targets for optimal care and for improving the quality of life for youth living with diabetes. Based on these findings, the NOPDP Advisory Committee recommended that staffing benchmarks for registered nurses, registered dietitians and social workers be increased by 25%, 40% and 50% respectively. Given the growing fiscal constraints in the Ontario healthcare system, these recommendations have not yet been implemented. The MHP-WG recognized that revisiting the issue of PDEP funding extends beyond the scope of this project; however, putting forth this recommendation emphasizes the importance of ensuring adequate funding for PDEPs in Ontario as human resource capacity can have a considerable impact on the paediatric diabetes teams' ability to meet the needs of their patients, such as addressing the mental health and psychosocial needs of children and youth living with diabetes. This recommendation takes into consideration that targeted investments are often most effective and that diabetes team members are well-positioned to identify and mitigate issues early on. Ensuring adequate funding for the PDEPs across the province would be an efficient use of taxpayer dollars that would impact the broader healthcare system. Targeted investments are often most effective and the diabetes team members are well-positioned to prevent the development of future and even more costly health, mental health and social issues in children, youth and families living with diabetes (e.g. eating disorders, lost productivity due to mental health and/or physical complications).

Next Steps

Implementation

Following the release of this recommendations report, the MHP-WG will proceed to the second phase of the project by conducting a prioritization exercise to determine which recommendations will be implemented by paediatric diabetes stakeholders across Ontario. Prioritizing the recommendations will be based upon factors such as their perceived value, ease of implementation, potential to enable system improvement, ability for system change, time constraints and cost implications (Provincial Council for Maternal and Child Health, 2013).

Once the prioritization exercise has been completed, the MHP-WG will develop an implementation strategy for the recommendations that have been identified as high priority. Toolkits and knowledge transfer mechanisms will be developed to support the implementation of the recommendations by diabetes teams, patients and families, LHINs, and the MOHLTC, as appropriate. This may entail having a select number of PDEPs pilot resources and tools that have been recommended. Furthermore, the implementation strategy will include an approach to stakeholder engagement that will foster consultation and collaboration, ensure that the necessary allocation of human, financial and capital resources are available, and help to raise awareness about the implementation of these recommendations across the province. These would be preliminary steps as obtaining buy-in from all stakeholders at every level of care is of paramount importance to ensure successful implementation and adoption of the recommendations that are deemed to be feasible.

Evaluation

It is important to conduct a formal evaluation from a provincial perspective to determine the degree to which the implementation of the prioritized recommendations is impacting patients and the system of diabetes care across Ontario. Establishing an evaluation framework can also help to uncover gaps that may not have been identified by the MHP-WG or emerging issues related to the mental health and psychosocial needs of paediatric diabetes patients and their families. It is also important to determine whether the implementation of the recommendations results in earlier identification of mental health needs and the effect it has on diabetes management. One potential approach to evaluation would be to determine patient and provider satisfaction with regards to the implementation of the resources that have been recommended. The MHP-WG has not yet embarked on the development of this evaluation framework.

Conclusion

Children and youth living with diabetes are at a significantly higher risk of developing mental health and psychological conditions such as anxiety, depression and eating disorders (Hood, Huestis, Maher, Butler, Volkening, & Laffel, 2006; Lawrence, et al., 2006; Fogel & Weissberg-Benchell, 2010; Colton, Olmsted, Daneman, & Rodin, 2013). Across the province of Ontario, children and youth, including those living with diabetes, face significant challenges in accessing mental health and psychosocial care. With these challenges comes the opportunity for paediatric diabetes care providers to effect change by collaborating with mental health practitioners, patients, families and other relevant stakeholders, to improve access and coordination of mental health and psychosocial care. The Mental Health and Psychosocial Working

Group developed a comprehensive set of evidence-based recommendations that aim to provide a more structured and streamlined provincial approach for access and coordination of mental health and psychosocial services for children and youth living with diabetes. As outlined in this recommendations report, this approach has the potential to cultivate a positive impact on the health and quality of life of children and youth living with diabetes in Ontario.

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Appendix 1 – Mental Health and Psychosocial Working Group Terms of Reference

Provincial Council for Maternal and Child Health
Paediatric Diabetes Network

Mental Health and Psychosocial Working Group

Terms of Reference

Background:
In Ontario, 15-20% of children and youth have a mental health need that manifests in a range of symptoms or impairment affecting productivity and activities of daily living. Amongst children and youth living with type 1 diabetes, the prevalence of mental illness including depression, anxiety, and eating disorders, increases to one third. The presence of mental illness, often occurring in combination with complex psychosocial conditions, can negatively impact diabetes management.

In terms of complexity of treatment and the level of family involvement required for successful management, diabetes is unique amongst chronic diseases in children in youth. Good metabolic control depends on a healthy psychological environment and an intact support system. Children afflicted by a mental illness and/or lacking psychosocial supports are at an increased risk for poor glycemic control which can lead to more rapid onset and progression of short-term and long-term health complications.

To ensure optimal diabetes management children require the support of an expert paediatric diabetes team including mental health specialists such as social workers and psychologists, and an approach to treatment that incorporates an understanding of the social and psychological implications of type 1 diabetes in youth. While this is widely recognized in Ontario, paediatric diabetes programs across the province indicate that providing or accessing adequate mental health and psychosocial supports for their patients is a major challenge in achieving the highest possible standard of care.

Purpose:
The Mental Health and Psychosocial Working Group (MHP-WG) will make recommendations regarding a provincial approach for paediatric diabetes programs to improving access and coordination of mental health and psychosocial services for youth and their families living with diabetes. Recommendations will be tailored to patients and families, paediatric diabetes teams, hospital and community mental health providers, Local Health Integration Networks, and the appropriate government ministries. The recommendations put forward will be generic so that they can be adapted to each patient, patient population, and the unique characteristics of an organization or the health system as a whole.

Objectives:
- To identify current issues in mental health and psychosocial care for children and youth with diabetes
- To identify current best practices in the provision of mental health and psychosocial services for children and youth with diabetes
- To identify and clarify the roles of secondary and tertiary paediatric diabetes teams and mental health and psychosocial service providers in hospitals and the community
- To recommend strategies to improve access and coordination of mental health and psychosocial services for children and youth with diabetes

- To prioritize strategies based on both importance and cost/ease of implementation
- To make recommendations regarding knowledge transfer and educational opportunities for mental health and psychosocial providers
- To look at opportunities for building synergies with existing partners in child and youth mental health and psychosocial services in Ontario
- To make recommendations regarding evaluation of the impact related to implementation of the recommendations

Accountability:
The MHP-WG will report to the Paediatric Diabetes Network Working Group (PDN-WG) of the Provincial Council for Maternal and Child Health (PCMCH).

Membership:
In order to ensure a comprehensive approach, MHP-WG members will be chosen from both secondary and tertiary paediatric diabetes programs, balanced by profession and organizational type.

Members:
- Social Workers from both secondary and tertiary Paediatric Diabetes Network teams (3)
- Psychologist familiar with paediatric diabetes (1)
- Clinicians working in mental health and psychosocial services in both hospitals and the community (Psychiatrist (≥1), Psychologists/Social Workers (1-2))
- A LHIN-based representative (1)
- Representative from the Ministry of Child and Youth Services (1)
- Representative from Children's Mental Health Ontario (1)

Given the focused nature of the group's work, alternates will not be permitted. The PCMCH Paediatric Diabetes Network Coordinator will provide support to the MHP-WG.

Decision Making Process:
Members share accountability for decisions. There should be open and direct communication based on honesty, respect and transparency, to ensure that all perspectives are heard. Decisions should be evidence or most-promising practice based. Decisions will be made by consensus whenever possible. If voting is required, all members will have one vote.

Conflict of Interest:
Members of the MHP-WG shall disclose, to the chair of their group, without delay, any actual or potential situation that may be reasonably interpreted as either a conflict of interest or a potential conflict of interest.

Communication and Confidentiality:
MHP-WG material should be treated as confidential. It will be clearly stated when MHP-WG material is no longer confidential.

Meeting Schedule:
October 2013 – March 2013

Appendix 2 – Mental Health and Psychosocial Working Group Membership List

Name	Profession	Organization	LHIN
Angela Bishop	MSW, RSW	Paediatric Diabetes Education Centre, Orillia Soldier's Memorial Hospital	North Simcoe Muskoka (12)
Sandra Dewar	Social Worker	Rouge Valley Health System (Scarborough, Centenary Site)	Central East (9)
Jess Forster (Co-Chair)	Social Worker	Paediatric Diabetes Education Program, Markham Stouffville Hospital	Central (8)
Erica Gold (Co-Chair)	Psychologist	London Health Sciences Centre - Children's Hospital	South West (2)
Heidi Haensel	Psychiatrist	London Health Sciences Centre	South West (2)
Jocelyne Marie Lauzon	Social Worker	Representing Children's Mental Health Ontario from The Phoenix Centre (Renfrew County)	N/A
Catherine Moore	MSW, RSW: secondary setting , several years in Paediatric Diabetes	William Osler Health Centre (Brampton)	Central West (5)
Donna Owens	Senior Policy Advisor	Ministry of Children and Youth Services, Children and Youth at Risk Branch	N/A
Ruth Slater (Co-Chair)	Psychologist	The Hospital for Sick Children (Toronto)	Toronto Central (7)
Greg Kennedy/Aryn Gatto	Senior Project Manager	Provincial Council for Maternal and Child Health	N/A
Callum Anderson (previous member)	Quality Improvement Facilitator	Central East LHIN	Central East (9)
Michelle Bloom (previous member)	Social Worker	Paediatric Diabetes Clinic, Trillium Health Partners (Mississauga Hospital)	Mississauga Halton (6)
Ruby Rowan (previous member)	Social Worker	Diabetes Care Centre Trillium Health Partners (Credit Valley Hospital)	Mississauga Halton (6)
Michelle Sorensen (previous member)	Clinical Psychologist, PhD	Queensview Professional Services	N/A
Evelyn Yu (previous member)	Social Worker	The Hospital for Sick Children (Toronto)	Toronto Central (7)

Appendix 3 – Lead Agencies for Child and Youth Mental Health in Ontario

MCYS Region	Service Area	Lead Agency
Central	Dufferin/Wellington	Canadian Mental Health Association Waterloo Wellington Dufferin Branch
	Halton	Reach Out Centre for Kids (ROCK)
	Peel	Peel Children's Centre
	Simcoe	New Path Youth and Family Counselling Services of Simcoe County
	Waterloo	Lutherwood
	York	Kinark Child and Family Services
East	Durham	Kinark Child and Family Services
	Frontenac/Lennox and Addington	Pathways for Children and Youth
	Haliburton/Kawartha Lakes/Peterborough	Kinark Child and Family Services*
	Hastings/Prince Edward/Northumberland	Children's Mental Health Services*
	Lanark/Leeds/Grenville	Children's Mental Health of Leeds and Grenville
	Ottawa	Youth Services Bureau of Ottawa
	Prescott & Russell	Valoris for Children and Adults of Prescott-Russell
	Renfrew	The Phoenix Centre for Children and Families*
	Stormont/Dundas/Glengarry	Cornwall Community Hospital
North**	Algoma	Algoma Family Services
	Kenora/Rainy River	FIREFLY – Physical, Emotional, Developmental and Community Services
	Nipissing/Parry Sound/Muskoka	Hands TheFamilyHelpNetwork.ca
	Sudbury/Manitoulin	Child and Family Centre/Centre de l'enfant et de la famille/Ngodweaangizwin Aaskaagewin
	Thunder Bay	Children's Centre Thunder Bay
Toronto	Toronto	East Metro Youth Services
West***	Brant	Woodview Mental Health and Autism Services
	Chatham/Kent	Chatham Kent Children's Services
	Elgin/Oxford	Oxford-Elgin Child & Youth Centre

	Essex	Hôtel-Dieu Grace Healthcare - Regional Children's Centre
	Grey/Bruce	Keystone Child, Youth & Family Services
	Haldimand/Norfolk	Haldimand Norfolk Resource, Education and Counselling Help (H-N REACH)
	Hamilton	Lynwood Charlton Centre
	Huron/Perth	Huron Perth Centre for Children and Youth
	Lambton	St. Clair Child & Youth Services
	Middlesex	Madame Vanier Children's Services

* Lead agencies identified in December 2015.

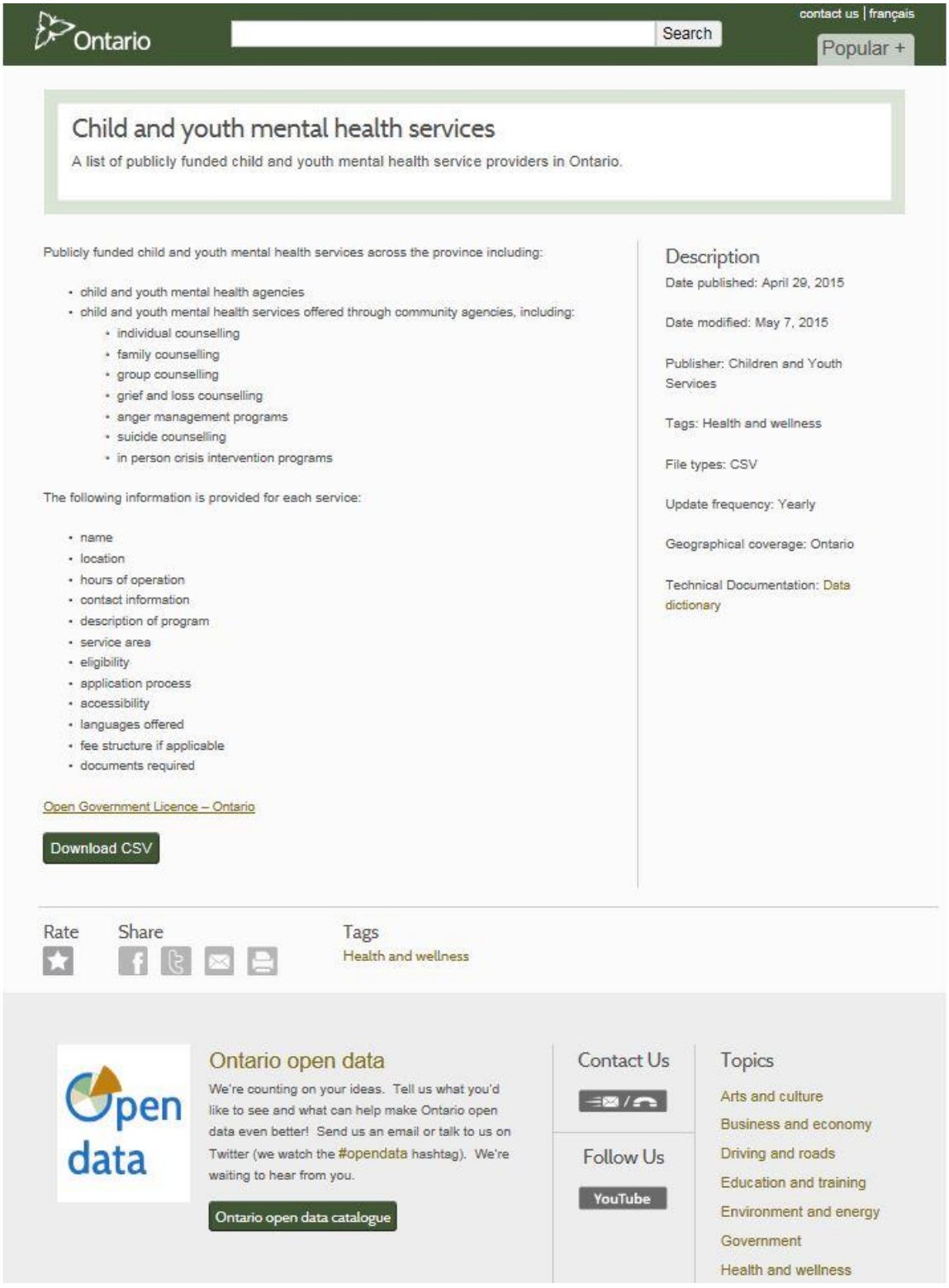
** Further work related to lead agency identification continues in Cochrane/Timiskaming.

*** An interim planning process is underway in the Niagara service area.

Retrieved from:

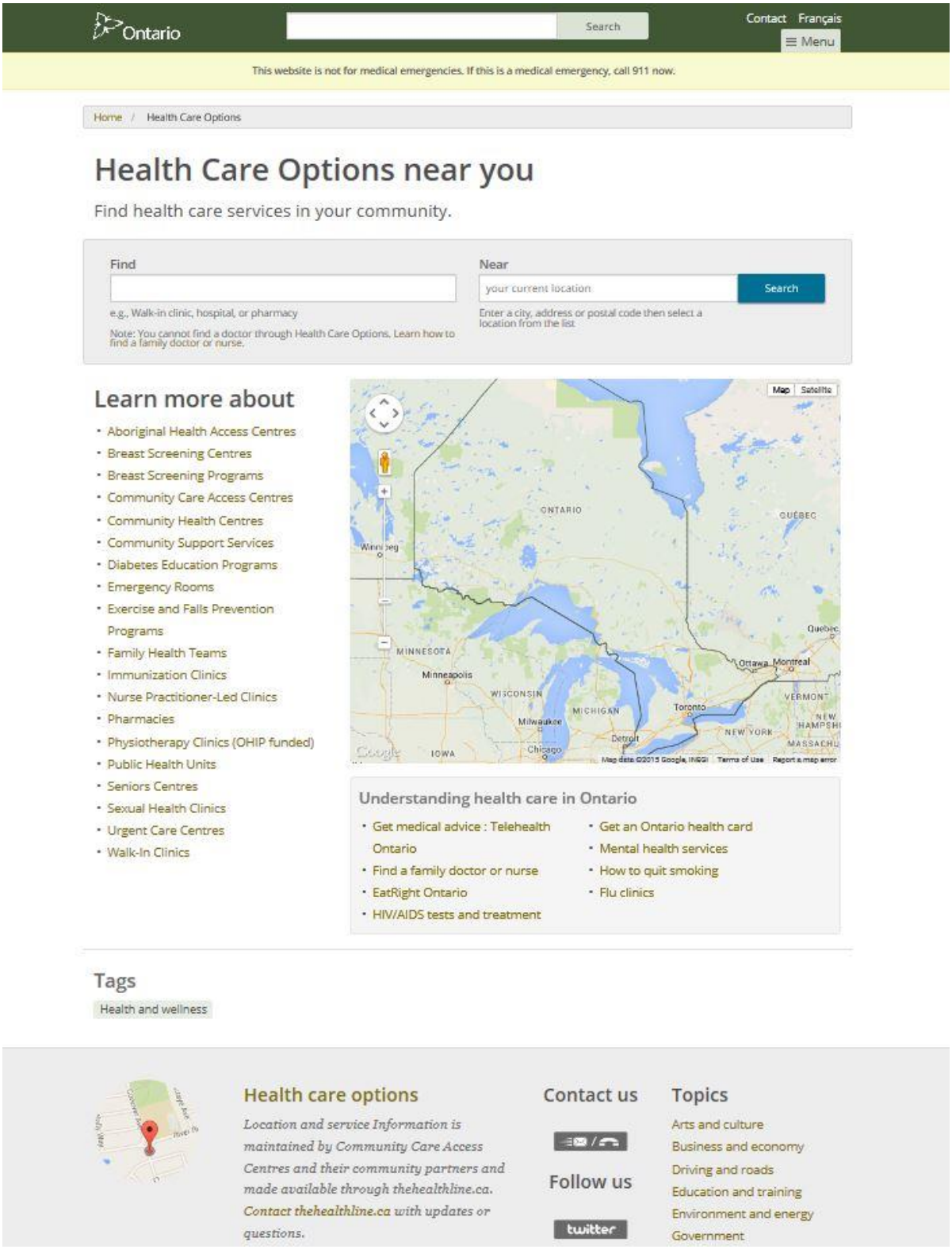
http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/mentalhealth/moving-on-mental-health.aspx

Appendix 4 – Open Data Catalogue for Child and Youth Mental Health Services



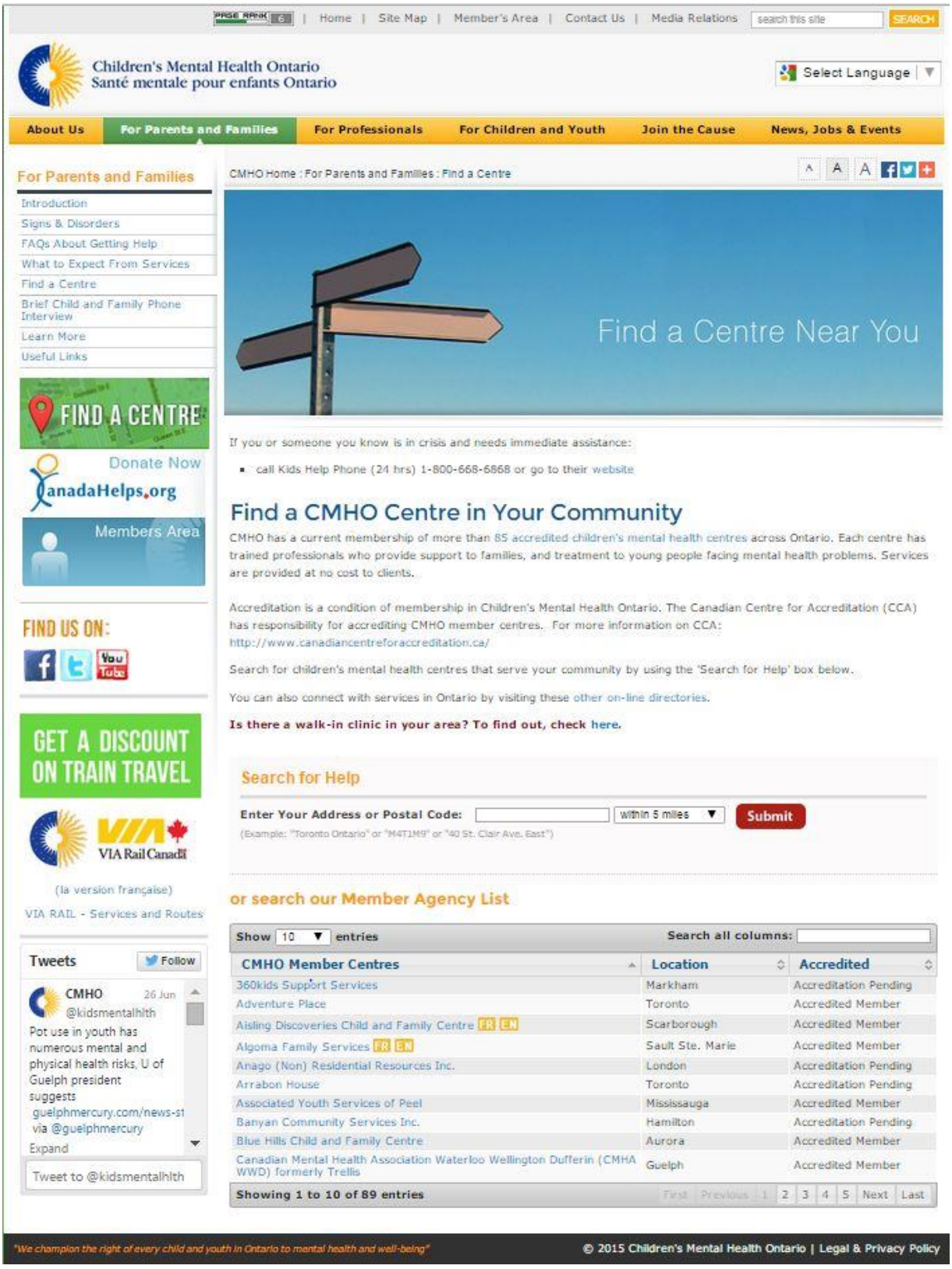
For the full list of publicly funded child and youth mental health service providers in Ontario, visit:
http://www.ontario.ca/data/child-and-youth-mental-health-services

Appendix 5 – Health Care Options



For more information, visit: http://www.ontario.ca/locations/health/

Appendix 6 – Children's Mental Health Ontario: Find a Centre



To learn more, visit: http://www.kidsmentalhealth.ca/parents/find_a_centre.php

Appendix 7 – Memorandum of Understanding for Managing Mental Health Conditions in Children and Youth with Diabetes

Managing Mental Health Conditions in Children and Youth with Diabetes

Memorandum of Understanding

Memorandum of Understanding
Between
<Name of Paediatric Diabetes Education Program>
And
Community Consortium Members
<Name of Community Agency>
And
<Name of Community Agency>

<Date>

Purpose:
This Memorandum of Understanding (MOU) will:

- Promote fair and timely access to children's mental health services for children and youth with diabetes being cared for by paediatric diabetes education programs (PDEPs).
- Ensure one common MOU between the PDEP and all community mental health agencies that service that PDEP.
- Prescribe the pathway of access and referral process on behalf of children and youth requesting mental health services from entry to the PDEP to child and youth mental health services.
- Establish clear guidelines for the nature and timeliness of community response to children and youth referred from the PDEP.
- Establish processes for communication of patient information and care planning.

Governing Principles:
Response to children and youth with a mental illness should be provided in the least restrictive and least intrusive means appropriate and in a manner that ensures the safety, privacy, dignity and self-respect of the youth, family and others.

Provision of prompt assessment and treatment for youth who are experiencing a mental health crisis is essential and timely follow-up may be required for many youth to ensure continued physical and psychological safety and wellbeing at home and in the community.

Inter-agency and cross-sectorial cooperation in assessment, intervention and coordination is essential to provide a comprehensive, efficient, and effective resolution, as well as facilitation of ongoing service delivery.

Continuity in the relationships between children and youth and their health care providers allows for the most comprehensive and informed treatment planning and management for children, youth, and their families. Where continuity in relationships may not be possible, information-sharing and coordination of services is essential.

To be effective, coordinated child- and family-centered care requires consideration of the unique needs of each child or youth, and his/her family and the community context.

Principles of the Partnership:
Appreciation of Diversity:

- The organizations appreciate the diversity of skills, perspectives, experience and knowledge brought to the partnership by the other(s). A partnership combines this diversity in a way that enables the partnership to think in new and better ways about how to service the community.

Valuing Relationship:

- Fundamental to the partnership success is the encouragement of relationships among leaders and staff from each organization. Relationship building opportunities are actively pursued among partner organizations at all levels.

Value Created:

- Partners do more than exchange resources – they create something new and valuable. This partnership will create value in that individuals will be served better across organizations/services.

Investment:

- Partnerships are relationships built over time and with shared experience. Partners show tangible signs of long-term and on-going commitment by devoting resources to the ongoing maintenance of the partnership.

Integrity:

- Partners behave towards each other in ways that justify and enhance mutual trust. Decisions will be made with the input of partners that will allow for compromise and consensus. Each partner has influence. Communication is open and constructive.

Collaboration:

- Inter-organization collaboration is aimed at producing and measuring better outcomes for people who use the service.

Excellence:

- Partners are strong in their commitment to this agreement and have something valuable to contribute. The motives for entering into this partnership are positive and of mutual benefit.

Parties to the Memorandum of Understanding:

The parties to this MOU are:

<Name of Paediatric Diabetes Education Program>

<Name of Community Agency>

<*Brief description of service rendered*>

<Name of Community Agency>

<*Brief description of service rendered*>

<Name of Community Agency>

<*Brief description of service rendered*>

Procedure/Process:

The PDEP will screen diabetes patients for mental health conditions at the following time points:

1) Initial screening to identify any mental health conditions or psychosocial concerns by the team's mental health provider as close to the time of diagnosis as possible.
2) At a minimum, on an annual basis thereafter, with consideration of the patient's age, developmental stage, individual traits and family characteristics.
3) Annually at a minimum with consideration of the diabetes patient's age, development stage, individual and family characteristics; At times of individual need, such as in response to emerging concerns, symptoms, or perceived risk factors during clinic visits.

Upon identification of a possible mental health condition at any time point the PDEP will complete a referral to the community agency and will share the following information:

- The patient's diabetes/mental health passport.
- Additional patient information deemed relevant (at the discretion of the PDEP).

The community agency will follow-up by telephone within _____ business days of receipt of PDEP information and make a determination regarding the urgency of community services required.

The community agency will keep the PDEP informed regarding follow-up response.

The community agency will notify the PDEP if there is termination of mental health services.

Communication Protocol:

Reciprocal communication between the PDEP and the community agencies is of paramount importance. This communication includes but is not limited to the results of PDEP screening tools, relevant medical information, as well as community agency follow-up response and treatment planning.

The communication mechanism and process will be left to the discretion of the parties involved. The mechanism should include a primary point of contact from the PDEP and the community agency, agreement on the frequency of communication, and agreement on the medium of communication.

Information Sharing and Privacy:

The parties of this MOU agree to comply with all relevant privacy-related legislation.

Where there is <u>disclosure</u> of personal information to a party of the MOU, they will ensure that:

- Informed consent to share personal information is obtained from the individual(s) and/or his/her guardian, where applicable.
- Personal information is disclosed in accordance with all applicable legislation pertaining to the personal information in question.

Where there is receipt of personal information to a party of the MOU and with respect to such personal information, they ensure that:

- All personal information received is used only in the manner and for the purposes for which the youth/guardian has consented;
- Appropriate security measures are in place to protect the delivery and storage of all personal information provided;
- They will comply with any reasonable recommendations made by governmental privacy authorities with respect to the protection of personal information provided.

Leadership:
Representatives from all organizations will meet annually, or at a frequency determined by the parties, to reaffirm the commitment to this agreement and provide future direction as well as discuss other related issues as they arise.

If trends emerge showing difficulty in responding to the needs of children and youth, the partners will develop strategies and/or recommendations to address such trends.

Operational Lead:
Each partner will identify an operational lead who will be the primary contact for their organization/service for purpose of the MOU and who will have the authority to act on behalf of his/her organization.

<Name of Paediatric Diabetes Team>

_____	_____	_____
Signature	Position	Date

<Name of Community Agency>

_____	_____	_____
Signature	Position	Date

<Name of Community Agency>

_____	_____	_____
Signature	Position	Date

Appendix 8 – Revised MyHealth Passport – Diabetes - Sample

Diabetes Health Passport	
Name	*John Smith*
Date of Birth	*June 30th, 1998*
Type of Diabetes	*Type 1 Diabetes*
Date of Diagnosis	*January 1st, 2005*
Do you have any other medical or mental health diagnoses?	*Obesity* *Depression*
Hospital visits	*Hosp adm for DKA in past 2 years: January 5th, 2013.* *Hosp adm for diabetes (DKA excl) in past 2 years: February 5th, 2013.* *Non-diabetes related hosp adm past 2 years: March 5th, 2013*
Type of Insulin	*Rapid acting insulin, I use an insulin pump with continuous insulin infusion*
Medication(s)	*Tylenol, Gravol*
Diet	*I count carbs, gluten-free diet,*
When my blood sugar is low, I feel:	*Dizziness, Shakiness, Headache, Grumpy, Treatment: Juice 50 mL, Treatment: 1 juice box, Treatment: Glucose tablets 1, Treatment: One slice of white bread*
When my blood sugar is high, I feel:	*Thirsty, Tired, Foggy*
Allergies	*Peanuts*
Screening	*Last 3 HbA1c: 7.0, 7.5, 8.0* *(this section should include a one-sentence narrative explanation, i.e. patient's target is 7.0 and lately has been steadily increasing)*
What are some of the challenges you face?	
Who manages your diabetes?	
Drug Coverage	*Trillium*
Pharmacy	*Shopper's Drug Mart, Ossington*
Exercise	*Soccer 2x per week*
Primary care provider	*Bob Johnson, 999-999-9999*
Diabetes care provider	*Janet Jones, 999-999-9999*
Special needs	
School Grade/Year	*11*
Learning challenges	
Primary language at home	
Cultural/religious considerations	
Emergency Contact	*Mother, Susan, 999-999-9999*
Date created/modified	

Appendix 9 – Mental Health & Psychosocial Triage Tool

Please note: This triage tool is intended as a guide. It is important to use your subjective sense as to whether a patient needs a referral to a mental health specialist. If the patient or their family has major difficulties but is already receiving community supports then the role of the team may be to liaise with the community supports. The questions listed in the tool could be posed by any staff on the paediatric diabetes team. Please see the tables that follow the triage tool if additional questions are required to elicit the needed information.

Section 1: Child's Family and Social Network		
Topic	**Questions (Potential Concerns)**	**Response*** *yes = a concern
a. General family structure	• Concerns about family structure that may make diabetes care more challenging (e.g., single parent, afterschool supervision issues, inconsistent parental work schedules)?	☐Yes ☐No
b. For children whose parents live separately	• Concerns about custody/access/decision making that could negatively affect diabetes care?	☐Yes ☐No
c. Social/ emotional aspects related to family	• Past or current CAS involvement? • Concerns about family adjustment to the diagnosis of diabetes? • Health beliefs that might interfere with the family's acceptance of the medical treatment or lead to feeling fatalistic about the child's future health? • Concerns about methods used to resolve conflicts/make decisions/allocate tasks to parents and children regarding diabetes? • Conflict between family members that will affect their communication with each other and their ability to effectively manage the diabetes? • Family has difficulty setting limits, feels sorry for their child or needs support in acknowledging child's feelings?	☐Yes ☐No ☐Yes ☐No ☐Yes ☐No ☐Yes ☐No ☐Yes ☐No
d. Family circumstances	• Concerns about insufficient income or lack of access to income supports needed for diabetes supplies and/or food? • Concerns about stress or lack of resources/supports in the broader social network? • Concerns related to immigration status/experiences?	☐Yes ☐No ☐Yes ☐No ☐Yes ☐No
e. Other	• Other concerns? If yes, please specify:	☐Yes ☐No

Section 2: Child's History and Current Status		
Topic	**Questions (Potential Concerns)**	**Response*** *yes = a concern
a. School	• Concerns about learning at school? • Concerns about behavior at school? • Social concerns at school? • Need for special education support?	☐Yes ☐No ☐Yes ☐No ☐Yes ☐No ☐Yes ☐No
b. Developmental history	• Concerns about development in speech/language, motor, social, intellectual, or other skills?	☐Yes ☐No

	• Concerns about feeding, eating, diet?	☐Yes ☐No
c. Behavioural/ social functioning	• Presence of significant organizational or communication challenges (e.g., autism, ADHD)? • Concerns about child/teen's response to direction/rules? • Concerns about substance use/abuse for the child/teen?	☐Yes ☐No ☐Yes ☐No ☐Yes ☐No
d. Coping/ emotional functioning	• Child/teen is experiencing high anxiety? • Child/teen has significant fears? • Child/teen is experiencing low mood? • Child/teen is experiencing sleep problems?	☐Yes ☐No ☐Yes ☐No ☐Yes ☐No ☐Yes ☐No
e. Specific stressors	• Child has experienced neglect/abuse? • Child has experienced significant loss(es)? • Child has experienced traumatic event(s)?	☐Yes ☐No ☐Yes ☐No ☐Yes ☐No
f. Other	• Other concerns? If yes, please specify:	☐Yes ☐No

Section 3: Other Family Members' History and Current Status		
Topic	**Questions (Potential Concerns)**	**Response*** *yes = a concern
a. Learning issues	• Parent/caregiver has difficulty learning that negatively impacts diabetes management?	☐Yes ☐No
b. Substance abuse	• Concerns about substance abuse within the family?	☐Yes ☐No
c. Mental health concerns	• Parent/caregiver is experiencing high anxiety? • Presence of mental health issues in parents/caregivers that might affect their ability to manage the diabetes (e.g., low or volatile mood, personality disorder, psychosis)? • Parent/caregiver has significant organizational or communication challenges (e.g., autism, ADHD)?	☐Yes ☐No ☐Yes ☐No ☐Yes ☐No
d. Specific stressors	• Parent/caregiver has experienced significant trauma? • Parent/caregiver is coping with significant loss(es)?	☐Yes ☐No ☐Yes ☐No
e. Adjustment to child's diagnosis	• Parent has overwhelming feelings of grief regarding their child's diabetes diagnosis that inhibits their ability to cope?	☐Yes ☐No
f. Other	• Other concerns? If yes, please specify:	☐Yes ☐No

Section 4: Family Strengths, Resources and Resiliency		
Topic	**Questions (Potential Concerns)**	**Response*** *no = a concern
a. Resources	• Any resources that the family can draw on to assist their coping (e.g., extended family, interests/activities, skills)? • Other? If yes, please specify:	☐Yes ☐No ☐Yes ☐No
b. Strengths	• Demonstration of sense of humour? • Demonstration of ability to regulate emotions?	☐Yes ☐No ☐Yes ☐No

	• Demonstration of ability to ask for help? • Demonstration of ability to problem-solve in new situations? • Other? If yes, please specify:	☐Yes ☐No ☐Yes ☐No ☐Yes ☐No
c. Resiliency	• Any past demonstrations of resiliency (e.g., particular challenges that have been managed well)? • If yes, please specify:	☐Yes ☐No

Additional Questions to Assist with Triage

Section 1: Child's Family and Social Network

a. General family structure

- *Who lives in the child's household?*
- *Does your child spend overnights with cousins, grandparents, friends? If the answer is yes, discover frequency.*
- *Who will be attending the intensive education sessions, and quarterly clinic team visits?*
- *Who will be helping the child with the tasks of diabetes care?*
- *Does your child come home after school, or attend a Daycare, or an afterschool program?*
- *Does your child participate in any sports/clubs at school, or in the community? When do these occur?*

b. For children whose parents live separately

- *What is the custody/access arrangement: there are many options here, and it is important the clinic be aware of each family's situation.*
- *Joint Custody is the most common form. The most salient feature of Joint Custody is the fact that parents share decision making rights.*
- *Joint Custody, with equivalent access. □Joint Custody, with differential access, □ Sole Custody, with access visits, □ Sole Custody, without an access visit schedule, □ Sole Custody with supervised visits.*
- *Blended family constellations are common, and can be intricate. Do ask about step-parents, step siblings, presence of new partner's extended family.*
- *Collaboration and open communication between divorced parents supports good diabetes management; to what extent does this describe your co-parenting?*

c. Social/emotional aspects related to family

- *Has CAS had involvement?*
- *Is there a history of physical/mental or verbal abuse within the family?*
- *How do you see your parental role in your child's diabetes care?*
- *Families and individuals have connections with relatives and friends. With whom do you keep in touch, celebrate and spend time with?*
- *How would you describe your community, or cultural background? Does your community have a perception of diabetes, of which you are aware?*
- *Can you tell us about the holidays you celebrate in your culture or faith community?*
- *Who are your closest supports; people with whom you feel sufficient comfort, trust and respect to discuss sensitive issues and concerns?*
- *Have you shared the diagnosis with your extended family, and friends? What was the response? How did it make you feel? Do you have any concerns with respect to disclosing your child's condition?*
- *Diabetes management involves a network of partnerships. Open communication between parents, or adults in the household regarding diabetes care tasks is really beneficial. How would you describe the decision making process in your household?(give examples, & further elaboration only if required)*
- *How do parents respond to misbehavior or to expressed anger from the child?*
- *How does the caregiver respond to the child/teen's emotions?*
    - *Ignores? Is overly solicitous? Is harsh? Acknowledges and remains calm?*
- *Is there a high degree of conflict expressed within the family?*
- *What do you find the most challenging or stressful in parenting your child? What is the most rewarding?*
- *Do you belong to a spiritual or faith community? Can you share any tenets/beliefs that have been helpful to you in this period of receiving the T1D diagnosis?*
- *Is there any history of uncontrolled diabetes in your family (nuclear or extended)?*
- *How do the child/teen and caregiver(s) interact during the education and clinic sessions?*
    - *Is the child/teen encouraged to speak for themselves?*
    - *Is the child/teen encouraged to ask questions?*
    - *Is the child/teen encouraged to offer a different view?*
- *How does the child/teen respond to caregiver demands?*
    - *Complies without any comment?*

- *Complies but states his/her own perspective or needs?*
- *Complies with vocal protest?*
- *Complies with physical protest?*
- *Does not comply?*

- *What is the general style of the caregiver when making requests of the child/teen?*
  - *□ Overly strict? □ Overly laissez-faire? □ Empathic but firm?*

d. Family circumstances

- *Income sources for the family?*
- *Parents work hours? Child care provisions during parent's working hours?*
- *Workplace benefits?*
- *Contact information for OW/ODSP worker, as the clinic must apply in writing for funds to cover the cost of pen needles. OW/ODSP worker needs to be made aware of T1D diagnosis as the program will reimburse for BG test strips, once the OMFH maximum of $825/annum is reached. Other supplemental benefits may be considered: i.e. Special Diet Allowance.*
- *Has the family immigrated to Canada?*
- *Has the family had a lot of moves? How many? Distance? Changing schools/friends?*

Section 2: Child's History and Current Status

a. School

- *How well does child/teen perform in school? Are there any concerns regarding school performance?*
- *Has the child/youth been involved in any special education programming or extra assistance with school work?*
- *Does your child have an Individualized Education Plan (IEP)? □ Yes □ No*
- *Are there any recent changes in school performance/attendance or any dramatic past changes?*
- *What are his/her favorite subjects/worst subjects? (include grades)*
- *Has the child/teen had to repeat any classes?*
- *Is there a history of skipping school or a high amount of sick time?*
- *Has the child/teen ever been suspended from school or dropped out?*
- *Is there any history of bullying at school or difficulty making/keeping friends?*
- *What are the child/teens future education/employment plans? (if applicable)*
- *Does the youth have any current or past employment? If so, any issues with employment e.g. termination, attendance record, issues with boss or coworkers?*
- *What are the child/teen's relationships like with teachers/employers?*

b. Developmental history

- *Do you have concerns about your child's development in any of these areas?*
  - *□ Speech or Language □ Motor Skills □ Social Skills □ Cognitive (Intellectual) □ Sensory □ Behavioral □ Emotional*
- *Does your child have any developmental delays or special needs? □ Yes □ No*
  - *Describe_____*
- *Does your child receive any special services (i.e.: Speech, O.T., Behavior Therapy, etc.)? □ Yes □ No*
  - *Describe_____*
- *How would you describe your child's feeding/diet?*
  - *□ Normal □ Picky Eater □ Restricted Diet □ Poor Nutrition*

c. Behavioural/social functioning

- *Does the child/teen participate in any activities/sports?*
- *Is the family affiliated with a church or other community group?*
- *Do parents have any concerns about their child/teen's behaviour? Do staff observe any concerning behaviour?*
- *How does the child/teen interact with others?*
- *Is he/she shy or outgoing? Does he/she have trouble making/keeping friends?*
- *How does the child/teen respond to direction?*
- *Are there any concerns regarding the child/teen's behaviour or response to rules?*
- *Is there any history of drug or alcohol use with child/teen?*

- *Does the youth have a boyfriend/girlfriend?*
- *How does the child/teen feel about sharing their diagnosis with others? How do parents feel about this?*

d. Coping/ emotional functioning

- *Does the child/teen have any problems sleeping? □ None □ Difficulty falling asleep □ Sleep continuity disturbance □ Early morning awakening*
- *Has the child/teen ever had any form of psychological treatment or counselling?*

If so, please elaborate: _____

- *Does the child/teen experience any form of anxiety or worries?*
- *Does the child appear sad or withdrawn?*
- *How does your child handle separation/transitions?*
- *Does your child have any fears? How does your child express these fears?*
- *When does your child get upset/angry?*
- *How does s/he express anger?*
- *Describe your child's typical temperament? □ Energy □ Sedentary □ Active □ Very active*
  Describe:_____
- *First Reaction (to new people, activities, ideas) □ Avoidant □ Shy □ Outgoing*
  Describe:_____
- *Mood (general emotional tone) □ Anxious □ Timid □ Curious □ Serious □ Happy □ Other:_____*

Describe:_____

- *Intensity (strength of emotional reactions) □ Withdraw □ Mild reactions □ Strong reactions*

Describe:_____

- *Adaptability (copes with transitions, changes in routine) □ Slow □ Flexible □ Quickly*

e. Specific stressors

- *Has the child experienced any abuse (physical/sexual/verbal)? If so, have they received counseling/treatment for this?*
- *Has the child experienced a traumatic event? (car accident, devastating events, suicide of a loved one?)*
- *Is the child/teen experiencing any grief/loss/bereavement? Have they suffered any loss in the past? How did they respond?*

Section 3: Other Family Members' History and Current Status

a. Learning issues

- *How well does the child/teen/caregiver take in and remember information?*
- *How much repetition is needed?*
- *How much simplification is needed?*
- *Are there signs of anxiety, sadness, attention, or other issues that seem to get in the way of learning or responding?*
- *What way of learning seems to work best for the child/teen/caregiver?*
  - *□ Verbal explanation? □ Diagrams? □ Demonstrations? □Apps or web-based material?*
- *How do you know if the child/teen/caregiver has understood?*
  - *□ Eye contact made/maintained? □ Questions raised for clarification? □ Demonstrates the skill independently?*
- *Are the child/teen/caregiver able to provide details of situations (such that you can picture it as if you had a "movie" of the scene)? Or are there details missing?*

b. Substance abuse

- *Is there a history of substance abuse in the family?*

c. Mental health concerns

- *Do any family members have a history of mental health concerns?*

E.g. Depression, anxiety, personality disorder?

d. Specific stressors

- *Have parents or any close family member experienced any trauma?*
- *Are any close family members struggling with the issues of Grief/loss/bereavement?*

e. Adjustment to child's diagnosis

- *Many parents describe feeling degrees of intense emotion when they are told their child has type 1 diabetes. Type 1 diabetes involves considerable family adjustments which parents must organize and supervise: how are the parents feeling about these changes and added responsibilities?*

Section 4: Family Strengths, Resources and Resiliency

a. Resources

- *Each individual and family is embedded in their own unique situation, having contact with various people and various services that can be of help to them in a time of need. What or who are the resources that you, or your child, or your family, can draw on to help cope with the demands of diabetes?*

b. Strengths

- *Each person has a combination of features that includes some things that they do well. What are the things you, your child, or your family, do well at or have had success with? These might be practical things, such as being able to do math calculations well, or they might be things related to personal style, such as patience or sense of humour.*

c. Resiliency

- *What are some of the challenges that you, or your child or your family, have faced in the past that have strengthened you as individuals? As a family? What experiences have contributed to your knowledge, to your level of understanding, and/or to your ability to cope with new challenges?*

Appendix 10 – Assessment and Screening Tools from the The DAWN MIND Youth Programme

DAWN MIND Youth Questionnaire (MY-Q)

Reference: Novo Nordisk (2010). DAWN MIND Youth Programme - A clinic's guide.

The MY-Q is a diabetes quality of life measure that assesses the following areas:

- Overall rating - "My life in general"
- Ratings of "My life" with respect to the way diabetes impacts:
    - School/work
    - Friends
    - Free time
    - Family
- Ratings of "Myself" with respect to:
    - Mood
    - Body & weight
- Ratings of "My Diabetes", including:
    - Worries
    - Satisfaction with management plan and diabetes team
    - Degree of difficulty of specific diabetes care behaviours
- Open-ended question about recent positive or negative events
- Open-ended question about any other issues

Problem Areas in Diabetes Survey – Parent Revised Version (PAID-PR)

Reference: Markowitz, J.T., Volkening, L.K., Butler, D.A., Antisdel-Lomaglio, J., Anderson, B.J., and Laffel, L.M.B. (2012) Re-examining a measure of diabetes-related burden in parents of young people with Type 1 diabetes: the Problem Areas in Diabetes Survey – Parent Revised version (PAID-PR) Diabetic Medicine, 29(4), 526-530.

Sample items from the PAID-PR:

- Feeling scared when I think about my child living with diabetes
- Feeling that my child is excluded from activities due to his/her diabetes
- Always worrying about what my child is eating

World Health Organization -Five Well-Being Index (WHO-5)

Psychiatric Research Unit
WHO Collaborating Centre in Mental Health

WHO (Five) Well-Being Index (1998 version)

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

	Over the last two weeks	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1	**I have felt cheerful and in good spirits**	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
2	**I have felt calm and relaxed**	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
3	**I have felt active and vigorous**	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
4	**I woke up feeling fresh and rested**	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
5	**My daily life has been filled with things that interest me**	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Scoring:

The raw score is calculated by totalling the figures of the five answers. The raw score ranges from 0 to 25, 0 representing worst possible and 25 representing best possible quality of life.

To obtain a percentage score ranging from 0 to 100, the raw score is multiplied by 4. A percentage score of 0 represents worst possible, whereas a score of 100 represents best possible quality of life.

Interpretation:

It is recommended to administer the Major Depression (ICD-10) Inventory if the raw score is below 13 or if the patient has answered 0 to 1 to any of the five items. A score below 13 indicates poor wellbeing and is an indication for testing for depression under ICD-10.

Monitoring change:

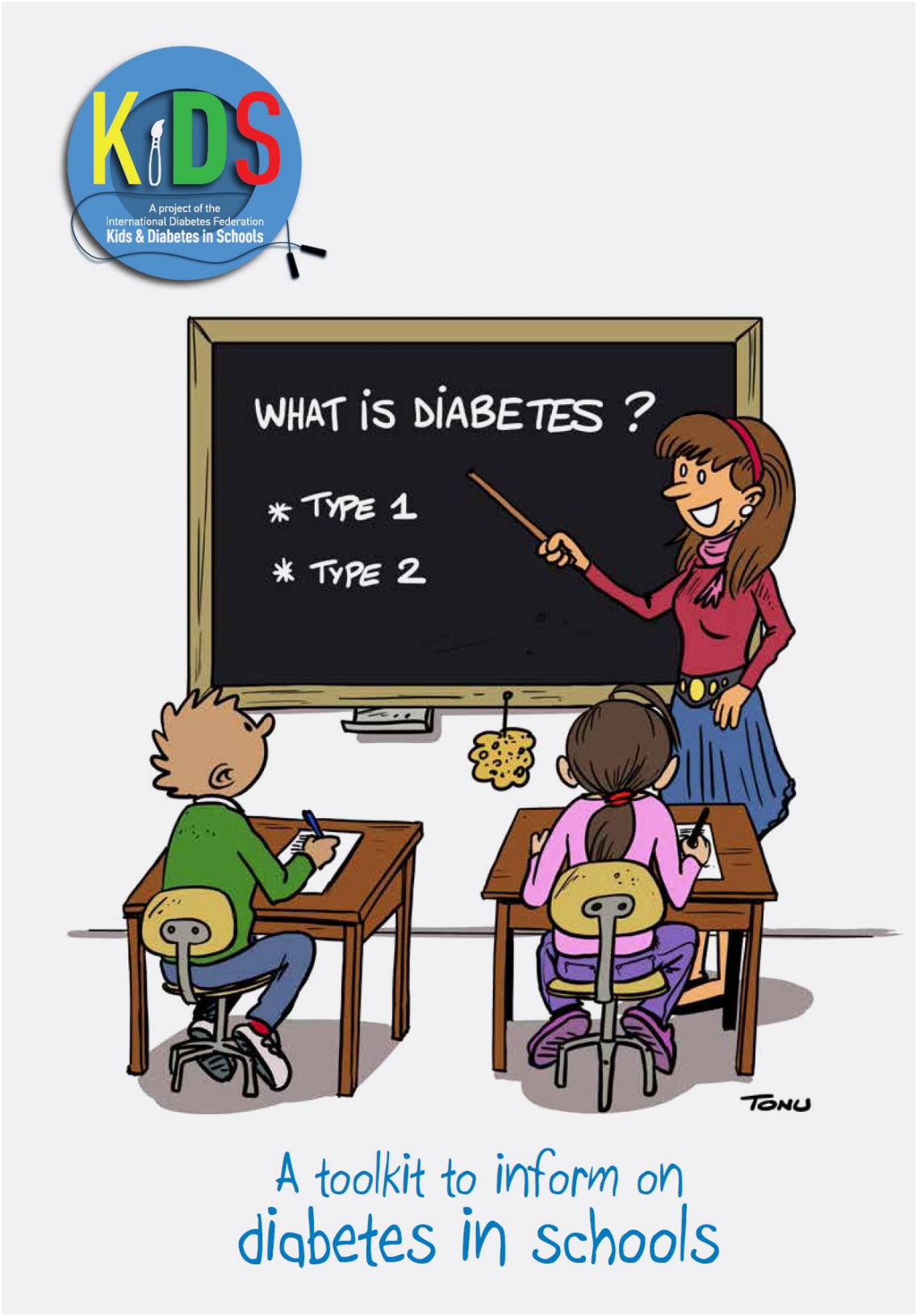
In order to monitor possible changes in wellbeing, the percentage score is used. A 10% difference indicates a significant change (ref. John Ware, 1995).

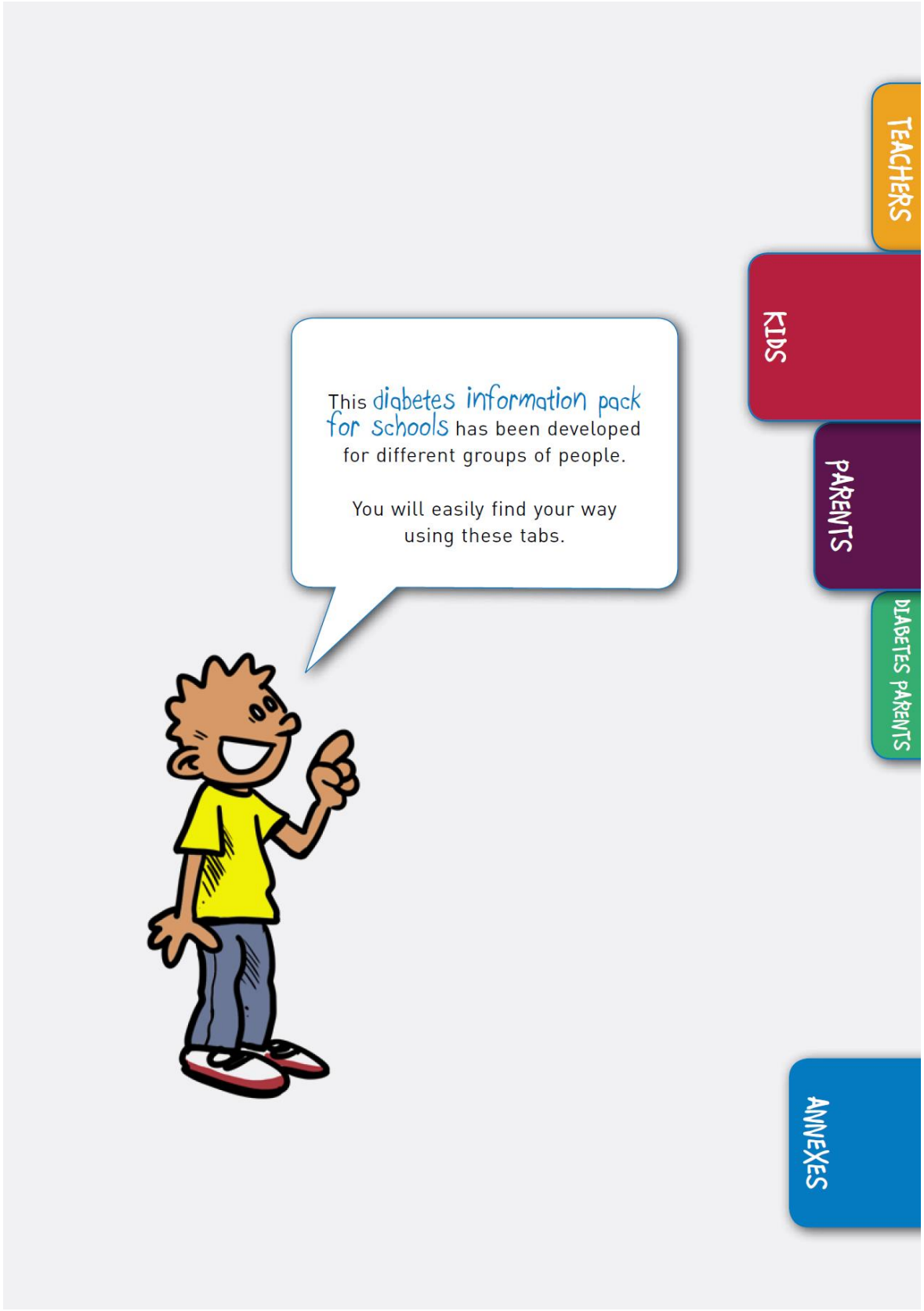
Appendix 11 – Additional Resources and Websites for the Online Resource Centre

Resource	Details
Canadian Diabetes Association (Canada)	http://www.diabetes.ca/
British Columbia's Children's Hospital Diabetes Handouts for Patients and Families (Canada)	http://www.bcchildrens.ca/Services/SpecializedPediatrics/EndocrinologyDiabetesUnit/ForFamilies/DiabetesHandouts.htm
Diabetes Care Program of Nova Scotia (Nova Scotia)	http://diabetescare.nshealth.ca/
eMentalHealth.ca (Canada)	www.ementalhealth.ca A non-profit initiative established by the Children's Hospital of Eastern Ontario dedicated to improving the mental health of children, youth and families.
Ontario Centre of Excellence for Child and Youth Mental Health (Canada)	http://www.excellenceforchildandyouth.ca/
Welcome to Type 1 (Canada)	http://www.welcometotype1.com/en-ca/ A website that promotes a proactive outlook and provides important information for those newly diagnosed with type 1 diabetes, either via video or the web.
Collaborative Mental Health Care (Canada)	http://www.shared-care.ca/ A website that provides up-to-date information on collaborative activities between mental health and primary care providers in Canada and other jurisdictions.
Tele-Link Mental Health Program (Canada)	http://www.sickkids.ca/ProgramsandServices/Tele-link/index.html
Working with Children and Youth with Complex Mental Health Needs: An Integrated Training Project (Canada)	http://complexneeds.ca/

A list of screening and assessment tools that were reviewed by Assessment and Screening Subgroup is to be compiled and included on the Online Resource Centre.

Appendix 12 – Kids Diabetes Information Pack for Teachers




This diabetes information pack for schools has been developed for different groups of people.
You will easily find your way using these tabs.
TEACHERS
KIDS
PARENTS
DIABETES PARENTS
ANNEXES

KIDS

A project of the International Diabetes Federation
Kids & Diabetes in Schools

information pack
for TEACHERS

A toolkit to inform on diabetes in schools

KIDS

A project of the International Diabetes Federation
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information pack
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A toolkit to inform on diabetes in schools

Acknowledgements:

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Partners :

International Diabetes Federation

ISPAD International Society for Pediatric and Adolescent Diabetes

Sociedade Brasileira de Diabetes

Associação de Diabetes Juvenil

PHFI Public Health Foundation of India

HRIDAY

Endorsed by:

Canadian Diabetes Association

The Canadian Diabetes Association supports the International Diabetes Federation's KiDS pack to ensure the health and safety of children with diabetes and to help them be full and equal school participants without fear of exclusion, stigmatization or discrimination.

IDF gratefully acknowledges the support of Sanofi in this project.

SANOFI DIABETES

KiDS
A project of the International Diabetes Federation
Kids & Diabetes in Schools

TEACHERS

Guidelines:

This pack should be used in tandem with an information session and is not intended to be distributed as a standalone item. A programme on diabetes education should be organised at schools around the pack.

If you wish to translate the pack into further languages or make culturally specific adaptations, please notify IDF before any changes are made: communications@idf.org.

IDF, ISPAD and Sanofi Diabetes logos must remain visible on this material. If you have a new local partner that endorses the project, make sure to seek IDF permission before adding new logos on the pack.

We would appreciate your feedback on pack usage and photos from your information sessions.

No fees will be asked for using this pack.

TABLE OF CONTENTS

TEACHERS

INTRODUCTION

TEACHERS

The following KiDS information pack will guide you in making the school environment a better place for children with diabetes. The pack is an awareness and information tool created to inform teachers and children about diabetes. This pack should be seen purely as an information resource and is not intended to replace the advice of the diabetes team.

Why a blue circle?

The icon was designed as a call to unite for diabetes and is a symbol of support for the UN Resolution on Diabetes. The colour blue represents the sky and it is the same colour as the flag of the United Nations

For the full information pack, visit: http://www.idf.org/kids-diabetes-information-pack-0

Appendix 13 – Guidelines for the Care of Students Living with Diabetes at School

Canadian Diabetes Association

Guidelines for the Care of Students Living with Diabetes at School*

Purpose:

To acknowledge and help clarify the essential roles and responsibilities among the Diabetes Care Team (DCT), which is comprised of the student living with diabetes, his or her parents/guardians, school personnel, and healthcare providers, in the care of students living with diabetes at school.

SUPPORT • CARE • EQUITY
DIABETES CHARTER FOR CANADA
Canadian Diabetes Association

Goals:

- To enhance the health, safety, emotional well-being and participation of each student with diabetes by providing information and guidance to the DCT regarding the student's diabetes management.
- To protect students with diabetes from stigma and discrimination by promoting a positive, caring, and inclusive learning environment through enhanced communication, education, and cooperation between all members of the DCT.
- To promote a positive sense of self and belonging and help each student with diabetes feel empowered to manage their diabetes effectively during school hours.
- To ensure each student with diabetes is not excluded from any school activities because of diabetes, unless indicated otherwise in the student's Individual Care Plan (ICP).

Issues of Concern:

- School-aged children with diabetes most often have type 1 diabetes and require insulin by injection or by a pump, throughout the school day.
- Some students, especially those that are very young, may be unable to check their own blood glucose (sugar) levels or administer their insulin while at school.
- There is an increased prevalence of school-aged children with type 2 diabetes who may require oral medication or insulin.
- Students with diabetes spend 30-35 hours per week in a school setting; this represents more than half of their waking weekday hours. It is therefore vital that the student, parent/guardian, school personnel, and healthcare providers are clear and confident in their roles and responsibilities during this time.
- It is important that the needs of each student with diabetes are recognized and accommodated according to the student's ICP.
- It is essential that school personnel have accurate and current information about diabetes and how it is managed to reduce stigma and other problems that may put a student's health and safety at risk.
- Dealing with issues related to diabetes, including attending medical appointments, may cause a student to be absent during school hours.

* Formerly the 2008 *Standards of Care for Kids with Type 1 Diabetes in School*. Approved by CDA National Board July 2014.

Cognitive Effects of High or Low Blood Glucose (Sugar) Levels:

Hypoglycemia (low blood sugar) and hyperglycemia (high blood sugar) may affect mood and behaviour and a student's ability to learn and to participate in school activities as well as lead to emergency situations, if left untreated.

Students with diabetes will learn and perform best when their blood sugar levels are within the target range outlined by their health care providers and indicated in the student's ICP. Blood sugar levels below or above this range can be associated with a decline in cognitive performance and ability. In order for a student with diabetes to learn and demonstrate their knowledge of a subject, including writing exams and performing other tasks for credit, blood sugar levels should be within their target range. If not, then an alternate time to redo or complete the activity should be provided.

Communication and Education

It is important that regular and ongoing communication is established between DCT members, so an effective change can be made for the student with respect to activities, special events or snacks/meals at school and to the student's ICP.

Roles and Responsibilities

Parents/Guardians or Student

- Notify the school of the student's diabetes diagnosis prior to attending school, or upon diagnosis, and arrange a meeting with the school principal. Include discussion of how to make other school personnel aware of the student's diagnosis.
- In cooperation with the school, arrange for diabetes education, training and resources that are consistent with current *Canadian Diabetes Association Clinical Practice Guidelines*, for all school personnel at diagnosis, on an annual basis, or as needed for any new staff members that are in contact with the student with diabetes.
- Students are encouraged to carry diabetes medical identification at all times.
- With the student's consent, arrange for a presentation to be made to classmates by the student or another member of the DCT about diabetes and how to identify symptoms of hypoglycemia/hyperglycemia.
- Provide at least 24 hours notice to school personnel of any change to the student's ICP, school routine, or of upcoming special events.

School Personnel

- Participate in annual diabetes education, training and resource review to learn or to be reminded of how to manage diabetes, including emergency procedures for treating moderate to severe hypo-

glycemia/hyperglycemia. The student's parent/guardian, diabetes education team and/or other trained healthcare providers could be invited to participate.

- Establish a formal communication system with all school personnel who come into contact with the student with diabetes. This should include appointing at least one staff member to be a point-of-contact for the student and parent/guardian.
- Identify the student with diabetes to all school personnel, including volunteers, substitute teachers, student teachers, and support staff. With permission from the student and parent/guardian, some schools may choose to display identifying information in the staff room or office and/or have emergency information folders made available to all personnel. These folders should contain the student's ICP, information about diabetes as well as information specific to the student. Medical alert stickers can also be placed on the student's file to further identify the student.
- Display posters identifying symptoms of hypoglycemia/hyperglycemia in key locations throughout the school.
- Provide at least 24 hours notice whenever possible to parent/guardian of any change in school routine or of upcoming special events.

Healthcare Providers

In cooperation with the parents/guardians:

- Provide posters identifying symptoms of hypo-glycemia/hyperglycemia to all school personnel.
- Act as a resource to the school to provide or arrange for diabetes education and training.
- Assist with the development of the student's ICP as needed.

Individual Care Plan (ICP)

A student's ICP provides specific information and instructions to school personnel regarding the student's daily diabetes management and diabetes emergency plans.

An ICP should contain the following information:

- Details informing school personnel, including regular and student/substitute teachers, support staff and volunteers that are in contact with the student on a regular basis, of the treatment guidelines and the type of medical care and monitoring required.
- The type of diabetes and diabetes medication/insulin.
- Frequency of blood sugar monitoring and target range.
- Symptoms commonly experienced for hypoglycemia/hyperglycemia, appropriate treatments and location of treatments.
- A plan for prevention of hypoglycemia during periods of increased or changes in activity.
- A readily accessible emergency procedure for the student, including emergency contact information and treatment procedures for severe hypoglycemia or hyperglycemia.
- Details regarding storage for emergency supplies including glucagon.
- Details regarding storage and accessibility of medical supplies and equipment that may be required for ongoing treatment.
- Details of a daily communication plan between the student, parent/guardian and school.

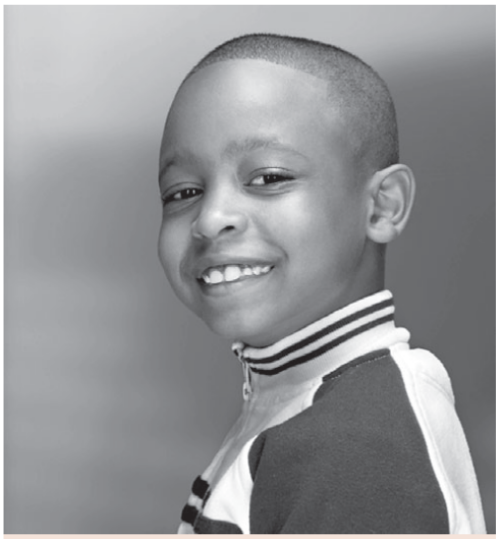
Roles and Responsibilities

Parents/Guardians or Student

- Meet with healthcare providers on a regular basis to develop and review the student's ICP to ensure daily management and emergency plans are indicated.
- Arrange a meeting with the school principal to review the student's ICP.
- Ensure the ICP is current.

School Personnel

- The school principal must meet with the student and parent/guardian to discuss the student's daily diabetes management requirements and the ICP while in school.
- The school principal must ensure the student's ICP is shared with or made available to all school personnel that are in contact with the student on a regular basis.



Ongoing Communication

Ongoing communication between the school and the student and parent/guardian is important to ensure the health and safety of the student and to allow parents/guardians to make necessary adjustments to the student's ICP.

Ongoing communication should include the following:

- Parents/guardians reporting to the school principal any changes to the student's ICP.
- School reporting to parent/guardian any issues of concern related to the student's diabetes management.
- School informing parent/guardian via a daily journal or communication log when student experiences hypoglycemia/hyperglycemia that requires assistance.
- School informing parent/guardian in advance of any change in usual school routine including, but not limited to, physical activity schedule, field trips, school bus schedule, changes in recess or lunch schedule.
- Daily communication between the student, parent/guardian and school according to the method and frequency indicated in the student's ICP.

Daily Management

To maintain optimal health, a student living with diabetes must balance medication, including insulin, food, and activity every day. A student experiencing hypoglycemia/hyperglycemia may be unable to perform school-related or other tasks. With support from school personnel, most students can manage their diabetes independently or with minimal support, however some students are unable to perform daily diabetes management tasks and may require trained personnel to administer insulin, monitor blood sugar, or supervise food intake and activity.

Blood Glucose (Sugar) Monitoring

School personnel can only perform blood sugar monitoring if there is mutual agreement with the parent/guardian as indicated in the student's ICP and if training is provided to school personnel.

Roles and Responsibilities

Parent/guardian and school personnel need to work together to establish a blood sugar monitoring plan to meet the student's needs. This should be reflected in the student's ICP.

Parents/Guardians or Student

- The student or parent/guardian is ultimately responsible for making decisions based on results of blood sugar monitoring.
- Provide very clear instructions to the school in the student's ICP for frequency of blood sugar monitoring.
- Provide or arrange for training to school personnel when required for checking blood sugar levels.
- Ensure that the student's blood glucose meter is in proper working order, with sufficient supplies available on a daily basis.
- Ensure a backup blood glucose meter is available with sufficient supplies.
- Ensure a sharps container is available for safe disposal of sharps.

School Personnel

- Permit the student or assigned trained personnel to check blood sugar conveniently and safely, wherever the student is located in the school or, if preferred by the student, in a private location.
- Notify parent/guardian if blood sugar monitoring supplies need to be replenished or if there is a concern regarding the working order of the blood glucose meter.

Medication Administration

Students with diabetes may require multiple doses of insulin by syringe, insulin pen or an insulin pump and/or oral diabetes medications while in school. Some students may require someone to supervise or administer insulin.

School personnel can only administer insulin or oral diabetes medications if there is mutual agreement with parents/guardians as indicated in the student's ICP and training is provided to school personnel.

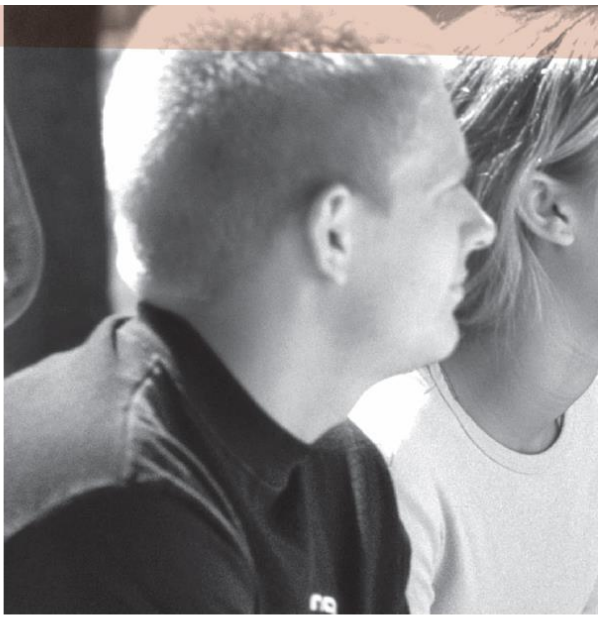
Roles and Responsibilities

Parents/Guardians or Student

- Provide or arrange for training to school personnel when required for insulin administration.
- Provide insulin dosing instructions to school personnel.
- Ensure a sharps container is available for safe disposal of sharps.
- Inform school personnel of changes to insulin and/or diabetes medication administration schedule and update the student's ICP.

School Personnel

- Supervise the student or administer insulin and/or diabetes medications when there is mutual agreement with the student or parent/guardian and training has been provided.
- Provide each student with a convenient, clean and safe location to administer insulin and/or diabetes medications and, if preferred by the student, in a private location.



Hypoglycemia (mild and moderate)

Hypoglycemia can be a result of too much insulin, delayed or missed meals or snacks, or more physical activity than usual without a corresponding increase in food or reduction in insulin.

Signs of Hypoglycemia

- Cold, clammy or sweaty skin
- Pallor (paleness)
- Shakiness, tremor or lack of co-ordination
- Irritability, hostility, poor behaviour, tearfulness
- Staggering gait (appearing drunk)
- Fatigue
- Confusion
- Loss of consciousness and possible seizure, if not treated early

Treatment of Mild and Moderate Hypoglycemia:

The student should immediately be given (if able to swallow) fast-acting glucose according to the student's ICP. **It is imperative that hypoglycemia is treated immediately as indicated in the student's ICP.**

Roles and Responsibilities

Parents/Guardians or Student

- Review annually with the school the student's ICP for treating mild and moderate hypoglycemia or whenever changes to the student's insulin or diabetes medication regimen are made.
- The student's ICP should define causes, prevention, identification and treatment of hypoglycaemia as it pertains to the individual child.
- Provide all snacks as well as an ongoing supply of fast-acting glucose for treating hypoglycemia.
- Encourage the student to keep a source of fast-acting glucose with them at all times.

School Personnel

- Understand that the symptoms of hypoglycemia can affect behaviour and the student's ability to perform school-related and other tasks.
- Ensure all snacks and meals are eaten on time, as indicated in the student's ICP. The student also requires adequate time to finish snacks/meals. A designated staff member may be required to ensure that the snack/meal is eaten.
- Treat hypoglycemia anywhere, at anytime, and during any activity immediately with available fast-acting glucose.
- Provide safe and readily accessible storage of the student's emergency snack supply.
- A readily available snack and supply of fast-acting glucose should be situated in several locations throughout the school. Ensure student has a source of fast-acting glucose with them at all times.
- Ensure the student is not left alone following the treatment of hypoglycemia until their blood sugar level has increased and is stabilized as indicated in the student's ICP.
- Ensure the student has adequate time to treat hypoglycemia prior to participating in any school activities as indicated in the student's ICP.
- Notify parent/guardian when treatment of mild to moderate hypoglycemia was required.

Roles and Responsibilities

Parents/Guardians or Student

- Review annually with the school the student's ICP for treating mild and moderate hypoglycemia or whenever changes to the student's insulin or diabetes medication regimen are made.
- The student's ICP should define causes, prevention, identification and treatment of hypoglycaemia as it pertains to the individual child.
- Provide all snacks as well as an ongoing supply of fast-acting glucose for treating hypoglycemia.
- Encourage the student to keep a source of fast-acting glucose with them at all times.

School Personnel

- Understand that the symptoms of hypoglycemia can affect behaviour and the student's ability to perform school-related and other tasks.
- Ensure all snacks and meals are eaten on time, as indicated in the student's ICP. The student also requires adequate time to finish snacks/meals. A designated staff member may be required to ensure that the snack/meal is eaten.
- Treat hypoglycemia anywhere, at anytime, and during any activity immediately with available fast-acting glucose.
- Provide safe and readily accessible storage of the student's emergency snack supply.
- A readily available snack and supply of fast-acting glucose should be situated in several locations throughout the school. Ensure student has a source of fast-acting glucose with them at all times.
- Ensure the student is not left alone following the treatment of hypoglycemia until their blood sugar level has increased and is stabilized as indicated in the student's ICP.
- Ensure the student has adequate time to treat hypoglycemia prior to participating in any school activities as indicated in the student's ICP.
- Notify parent/guardian when treatment of mild to moderate hypoglycemia was required.

Severe Hypoglycemia

Severe hypoglycemia in the school setting is rare, but it is important that staff understand how to respond quickly. Severe hypoglycemia is an emergency situation and often requires the administration of glucagon.

School personnel should be trained to administer glucagon if there is mutual agreement with parents/guardians as indicated in the student's ICP and training is provided to school personnel.

Roles and Responsibilities

Parents/Guardians or Student

- Provide a glucagon kit to the school and ensure it is replaced before it expires.
- Provide for glucagon injection training by a health-care provider for designated staff.
- Review annually with the school the student's ICP for emergency procedures for treating mild or moderate hypoglycemia or whenever changes to the student's insulin or diabetes medication regimen are made.
- The student's ICP should define causes, prevention, identification and treatment of hypoglycemia as it pertains to the child.

School Personnel

- Call 911 immediately and notify parent/guardian.
- Never give food or drink to a student who is unconscious or otherwise unable to swallow!
- Ensure at least two designated staff are trained to administer glucagon.
- Safely store a readily accessible supply of glucagon.
- Notify parent/guardian when glucagon kit is near expiry date.
- Administer glucagon according to instructions in the student's ICP.

Hyperglycemia

Hyperglycemia occurs when blood sugar levels are higher than the student's target range and can be caused by too little insulin or other diabetes medication; extra food not balanced with an adequate amount of insulin and/or diabetes medications; decreased physical activity; physical or emotional stress, infection, injury or illness; or insulin pump malfunction. Emergency treatment is usually not required except in the case of diabetic ketoacidosis (DKA) (*see Severe Hyperglycemia below*).

Signs of Hyperglycemia

- Increased thirst
- Increased urination
- Change in appetite or nausea
- Blurry vision
- Fatigue
- Irritability, hostility, poor behaviour, tearfulness

Roles and Responsibilities:

Parents/Guardians or Student

- Provide target blood sugar levels in the student's ICP to the school.
- Provide instructions for when blood sugar is above the target range.
- Students using an insulin pump with blood sugar reading greater than 15.0 mmol/l should check for ketones and notify their parent/guardian, unless otherwise indicated in the student's ICP.

School Personnel

- Notify parent/guardian if the student has consistently high blood sugar levels according to the student's ICP.
- Discuss the treatment of hyperglycemia with the parents/guardians.
- Provide opportunities for the student to deal with the symptoms as necessary, including access to the washroom or to drink water more frequently.
- Additional blood sugar checking as well as ketone checking may be required. Permit the student to check blood sugar and ketones conveniently and safely, wherever he or she is located in the school or in a private location according to the student's ICP.
- Administer supplemental insulin according to the student's ICP.
- Understand that the symptoms of hyperglycemia can affect behaviour and the student's ability to perform school-related and other tasks.

Severe Hyperglycemia

Untreated hyperglycemia may lead to the emergency situation diabetic ketoacidosis (DKA). Parents/guardians should be called if a student is nauseous, vomits or shows signs of illness.

Symptoms of Diabetic Ketoacidosis (DKA)

- Dry mouth, fruity breath, extreme thirst, and dehydration
- Increased urination
- Nausea and vomiting
- Severe abdominal pain
- Shortness of breath
- Sleepiness or lethargy
- Depressed level of consciousness

Roles and Responsibilities

Parents/Guardians or Student

- Ensure the student's ICP includes an emergency plan and that all school personnel who work with the student have access to the plan and have been trained to recognize and respond to symptoms of severe hyperglycemia.

School Personnel

- Notify parent/guardian if the student is unable to eat or vomits at school, or shows signs of illness.
- If the student vomits and parent/guardian is unavailable, call 911 immediately or take action according to the student's ICP.

Nutrition/Food

The balance of food, medication and activity is essential to achieving optimal blood sugar control. Timing and quantity of food is based on the individual student's ICP. Missing a meal or snack or eating less than planned may result in hypoglycemia. Conversely, eating more food than planned may result in hyperglycemia. The student's food intake may need to be consistent or it may be flexible when insulin dose is administered based on food intake. With planning, a student with diabetes can enjoy the same foods as everyone else. Unless indicated in the student's ICP, there are no "forbidden" foods.

Roles and Responsibilities

Parents/Guardians or Student

- Inform the school of the student's meal plan including time, type and quantity of food and include this information in the student's ICP.
- Inform the school of any special food restrictions such as in the case of celiac disease or food allergies.

School Personnel

- Ensure all meals and snacks are eaten completely and on time. Provide sufficient time for the student to finish snacks/meals.
- In the case of younger students, provide supervision to ensure entire meal/snack is consumed.
- Communicate to parent/guardian situations where food was not eaten or where there were changes to planned food intake due to school-related activities.

Physical Activity, Sports and Extracurricular Activities

Students with diabetes should be encouraged to be participants in all school activities. Planning is essential, so that blood sugar levels are maintained within a safe target range; the major risk of both planned and unplanned activity is hypoglycemia.

In cases of unplanned activity, eating an extra snack may be necessary. Exercise, sports and extracurricular activities are three of many factors which may affect an individual's blood sugar levels. If activities are found to affect blood sugar levels in a predictable manner then, at the request of parent/guardian and according to the student's ICP, insulin administration may differ from the usual regimen during certain specified activities.

Roles and Responsibilities

Parents/Guardians or Student

- Determine any required changes from the usual regimen during periods of physical activity, sports or extracurricular activities and provide clear instructions to the school in the student's ICP for such activities. For example, any changes to insulin doses should be specified.
- Ensure that the student's ICP indicates when physical activity should be restricted based on blood sugar levels being too low or too high.
- Provide for extra snacks (e.g. carbohydrates) clearly marked for days the student is involved in extra activity.

School Personnel

- Inform parent/guardian of any extracurricular activity, so that plans can be made around diabetes management.
- Have a readily available supply of fast-acting glucose for treatment of low blood sugar.
- Recognize that there is often a higher chance of hypoglycemia in the hours following intense physical activity and other intense activities and be alert to any signs of hypoglycemia in the student.

GLOSSARY

- **Blood glucose:**
  The amount of glucose (sugar) in the blood at a given time. It is important that blood sugar levels do not go too low or too high. Checking blood sugar helps students with diabetes balance between food, activity and medication.

- **Blood glucose monitoring/self-monitor blood glucose (SMBG)/monitor:**
  Students with diabetes monitor their blood sugar often and regularly with a glucose meter. A drop of blood is placed on a blood glucose test strip inserted into the meter to obtain a reading. Students with diabetes are encouraged to keep a meter with them and if they experience changes in behaviour or symptoms of low or high blood sugar, they should "check, don't guess." Some students, especially those who are very young, may be unable check their own blood sugar.

- **Clinical Practice Guidelines:**
  The Canadian Diabetes Association's Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada (*CPGs*) are evidence-based clinical practice guidelines intended to help healthcare professionals provide the best in patient-centered diabetes care and chronic disease management. Recognized internationally and updated every five years, the CPGs provide recommendations on screening, prevention, diagnosis, education, care and management of diabetes.

- **Diabetes management/self-management/daily management:**
  A cornerstone of diabetes care in order for students to live well with diabetes and to prevent or delay complications of diabetes. It involves following prescribed medication, diet and physical activity patterns, checking blood glucose and adjusting treatments. Students and their parents/guardians are encouraged to be actively involved in the decision making around the student's diabetes care.

- **Diabetic ketoacidosis (DKA):**
  DKA is life-threatening and occurs when blood sugar levels are too high and the body breaks down fat for energy. This leads to a high level of ketones in the body. At high levels, ketones are poisonous and can lead to coma or death, if not treated.

- **Fast-acting glucose:**
  A rapidly absorbed source of carbohydrate to eat or drink for the treatment of mild to moderate hypoglycemia or low blood sugar (e.g. glucose tablets, juice). A source of fast-acting glucose should be kept with a student at all times as well as in easily accessed locations throughout the school.

- **Glucagon:**
  A hormone that raises blood sugar. An injectable form of glucagon is used to treat severe hypoglycemia. Training by a healthcare provider is required to administer glucagon.

- **Glucometer:**
  A medical device used to measure the concentration of sugar in the blood.

- **Glucose:**
  Is the fuel that the body needs to produce energy. Glucose (sugar) comes from carbohydrates such as breads, cereal, fruit and milk. To use this sugar, the body needs insulin. Almost all foods contain carbohydrates.

- **Hypoglycemia/low blood glucose (*mild or moderate*):**
  An urgent and potentially emergency situation that occurs when the amount of blood glucose (sugar) has **dropped below** a student's target range (e.g. 4.0 mmol/l). Hypoglycemia can be mild, moderate or severe. Hypoglycemia requires treatment with a fast-acting glucose and rechecking of blood sugar until levels have stabilized within the target range. Hypoglycemia can be a result of having injected too much insulin, or eaten too little carbohydrate, or engaged in unplanned physical activity.

- **Hypoglycemia/low blood glucose (*severe*):**
  An urgent situation requiring assistance of another person and an emergency response. A student displaying symptoms of fainting, seizure, and difficulty speaking requires an emergency response.

- **Hyperglycemia/high blood glucose:**
  When the amount of blood glucose (sugar) is higher than an individual's target range. The student may be thirsty, urinate more often, and be tired.

- **Individual Care Plan (ICP):**
  A standardized plan that includes details informing school personnel and others who are in direct contact with the student on a regular basis (as well as being available to all substitute personnel) of the type of medical care and monitoring required, and treatment guidelines. The student's ICP also includes a readily accessible emergency procedure for the student, including emergency contact information, storage instructions for glucagon and other emergency supplies, as well as details regarding storage and accessibility to medical supplies and equipment that may be required for ongoing treatment of the student's diabetes. The student's ICP also provides information about what the student will need to do during the school day, for example checking blood sugar, taking insulin injections or oral medications, eating snacks and lunch at a certain time each day and planning for activities. The student's ICP should also outline the support a student will need with their diabetes management activities and who will be responsible to provide it while in school or participating in school activities.

- **Insulin:**
  A hormone required to convert glucose (sugar) to energy for the body to use. Without insulin, sugar builds up in the blood instead of being used for energy. Students with type 1 diabetes must administer insulin by syringe, insulin pen or insulin pump. Some students with type 2 diabetes may also require insulin.

- **Insulin Pen:**
  A device for injecting insulin for the treatment of diabetes.

- **Insulin Pump:**
  A medical device for delivering insulin. Insulin pumps are small portable battery-operated devices worn on a belt, put in a pocket or attached directly to the skin.

- **Ketones:**
  Ketones are produced by the body when there is no insulin or not enough insulin in the body. The body uses fat for fuel instead of glucose and this makes ketones. Ketones can make the student feel sick and can lead to a serious illness called DKA (Diabetic ketoacidosis). Ketones should be checked, using a blood ketone meter or urine ketone strips, when the blood sugar is above 13.9 mmol/l.

- **Sharps:**
  Used insulin syringes, insulin pen needles and lancets for blood glucose monitoring are sharp items that must be disposed of carefully and in appropriate sharps containers.

- **Target range:**
  Acceptable blood sugar levels based on the *Canadian Diabetes Association's Clinical Practice Guidelines* and personalized for the student by parents or guardians and the DCT.

- **Type 1 diabetes:**
  Usually diagnosed in children and adolescents, it is an autoimmune disease in which the pancreas stops producing insulin. The cause of type 1 diabetes remains unknown and it is not preventable.

- **Type 2 diabetes:**
  Once a condition that occurred only in adults, it is now being diagnosed in teens and even in children. Type 2 diabetes is a disease in which the pancreas does not produce enough insulin, or the body does not properly use the insulin it makes.

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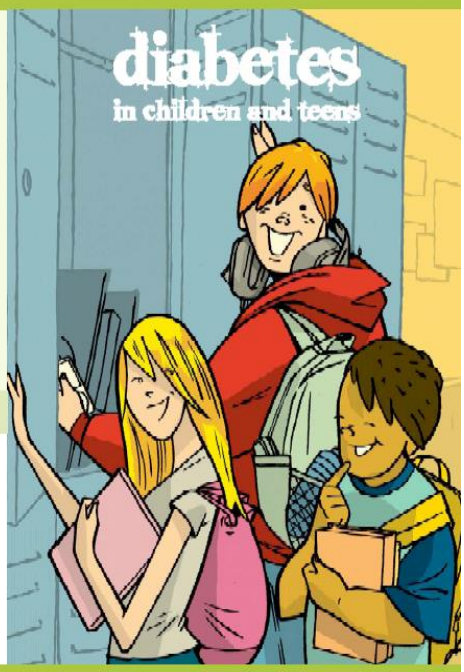
Appendix 14 – Diabetes in Children and Teens: A Survival Guide

when to call parents

A SURVIVAL GUIDE

- A low blood sugar that requires assistance - If the student needs assistance to manage a low blood sugar or if it takes them longer than 15 minutes to recover from a low blood sugar.
- Illness - If the student is unwell at school, phone parents immediately. If you are unable to reach them, call 911, be sure to tell EMS the student has type 1 diabetes.
- If there are frequent low blood sugars - If the student is experiencing several low blood sugars a week.
- If diabetes supplies are depleted - The student must have a reserve of fast acting sugar at the school at all times.
- If blood sugars are out of range - The student's individual school diabetes plan should indicate when parents need to be notified
- If the insulin pump is beeping - Allow the student to call their parents to problem solve any issues related to the pump with out delay.



to learn more about type 1 diabetes

View the DVD that accompanies this pamphlet " Diabetes in the Classroom".

www.diabetes.ca
www.diabetes.org
www.jdrf.ca

Trillium Health Centre would like to gratefully acknowledge Sears Canada for their generous contribution and making a difference for children with diabetes.
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Trillium HEALTH CENTRE

SUPPORTING STUDENTS WITH TYPE 1 DIABETES IN THE CLASSROOM

THIS GUIDE WAS DEVELOPED TO PROVIDE SCHOOL STAFF WITH GENERAL INFORMATION ABOUT TYPE 1 DIABETES. IT IS HOPED THAT STAFF WILL FEEL COMFORTABLE PROVIDING THE NECESSARY SUPPORT AND ACCOMMODATIONS, SO STUDENTS WITH TYPE 1 DIABETES CAN LEARN IN AN ENVIRONMENT THAT IS SAFE AND SUPPORTIVE.

type 1 diabetes

type 1 diabetes cannot be cured, but it can be well managed. There are certain activities a student with type 1 diabetes must do to help keep their blood sugars in a healthy range.

- is one of the most common chronic diseases of childhood. It develops when the body's immune system destroys the insulin producing cells of the pancreas. Insulin is an essential body requirement and without it, the body cannot use food for energy. Type 1 diabetes can only be managed by taking insulin injections.

In contrast, type 2 diabetes develops when the pancreas does not produce enough insulin or the insulin produced is not used effectively. It develops more frequently in adults and can often be managed with exercise and pills.

Staying healthy means keeping blood sugar levels as close to normal as possible. The three main variables of control are food, insulin & exercise.

Food
Raises blood sugars.
The student must eat measured amounts of carbohydrates at certain times of the day in order to balance the injected insulin.

Exercise
Usually lowers blood sugars.
The student may take some juice or a snack before an activity to prevent a blood sugar from going too low.

Insulin
Lowers blood sugars.
Insulin must be taken by injection, or by wearing an insulin pump. Younger students do not usually take insulin injections at school.

Eat

Food is like medicine to the student with diabetes

To avoid a low blood sugar, it is important that:

- The student has sufficient time to eat their food.
- Snacks or lunches are not delayed or missed.
- All of the snack / meal is eaten.
- Adult supervision may be required for a younger student.

- The student needs to be able to check their blood sugar and take their insulin in a safe, convenient location, where they feel comfortable.
- They need a safe place to store their supplies.

Check Blood Sugar

- The student will usually check their blood sugar level using a special meter; before eating a meal / snack and whenever they feel unwell.

Take Insulin

- The student may have to take an injection of insulin at lunch time using either an

INSULIN SYRINGE

- Insulin syringes are specially made syringes for self injection of insulin

INSULIN PEN

- Insulin pens look like a pen and allow the student to dial in the desired dose.

INSULIN PUMP

- The student who wears an insulin pump receives insulin continuously via a small catheter placed under the skin.

The student must press buttons on the pump to receive the correct dose of insulin.
The pump must be worn 24 hours a day and can only be taken off for short periods such as gym.

Hypoglycemia

Low blood sugar signs and symptoms

Hypoglycemia (low blood sugar)

When supporting a student with type 1 diabetes the emergency situation you are most likely to encounter is a Low Blood Sugar also know as a hypoglycemic reaction or insulin shock.

A low blood sugar means that the level of sugar present in the blood is inadequate for the brain to function properly. When the brain detects the blood sugar level as being too low it sends cues or signals to the student to alert them.

On the student's school plan there should be a description of how the student will feel when they are experiencing a low blood sugar. Every student will have their own unique signs and symptoms of feeling low (see opposite page).

Low blood sugars can occur at any time and any place. They are not always predictable or preventable so being prepared is the key.

How to keep a student with type 1 diabetes safe

Know which student has type 1 diabetes

- Encourage the student to wear their medic alert bracelet

Be alert to the changes that signal a low blood sugar

- If the student looks unwell, acts strangely or states they feel low, stay with them and allow the student to check their blood sugar

Know what might cause a low blood sugar

- Insufficient food due to a delayed or missed meal
- More exercise than usual
- Too much insulin

Know how to treat a low blood sugar

- At the first sign of a low blood sugar allow the student to check their blood sugar level using their meter
- If the reading on the meter is below 4.0 ensure the student takes their fast acting sugar immediately.

Some examples are:

175mls (6oz) juice or pop (not diet)
or 5-6 lifesavers
or 3 glucose tablets or as directed by parent

Understand that the student is in a very vulnerable state when their blood sugar is low.

- The student whose blood sugar is low may not be able to think clearly. They need to be supervised, by an adult, until they feel better. This can take up to 15 minutes. If the student doesn't feel better after 15 minutes ask them to recheck their blood sugar level. If the reading is still below 4.0 repeat the above action and call their parents.

If in doubt manage as a low blood sugar

- If the student looks unwell, acts strangely or states they feel low and is unable to check their blood sugar, manage the situation as a low blood sugar.

Hyperglycemia

High blood sugar signs and symptoms

Hyperglycemia (high blood sugar)

Blood sugar levels are constantly changing. Someone who does not have type 1 diabetes is able to automatically adjust the amount of insulin their body requires to keep their blood sugars within a tight range. When someone develops type 1 diabetes they lose the ability to internally regulate their blood sugar levels because their pancreas no longer makes sufficient insulin. The student must try to control their blood sugar levels using injected insulin. It is not always easy to control blood sugars using injected insulin because there are many factors that influence blood sugars that cannot be controlled.

Inevitably there will be times when the student will experience blood sugar levels that are too high. A blood sugar >14 is usually considered too high but refer to the student's plan for individual parameters. The earliest and most obvious symptoms of a high blood sugar are increased thirst and urination (see opposite page). A high blood sugar is NOT an emergency but it may require accommodations in the classroom.

What can cause a high blood sugar?

- Too much food
- Illness
- Stress
- Growth spurts
- Less than the usual amount of exercise (indoor recess)
- Not enough insulin / insulin pump not working
- Sometimes we don't know why the blood sugar is too high!

What can I do to help the student whose blood sugar is too high?

Understand that the student may feel unwell when their blood sugar level is high. Allow the student to check their blood sugar since symptoms of a high blood sugar can be confused with symptoms of a low blood sugar. Understand that these symptoms are beyond the control of the student.

- Allow the student to drink water at their desk
- Allow the student to have open bathroom privileges
- Understand that the student may feel irritable & tired, which can impact their academic performance
- See the student's school diabetes plan, parent may need to be notified.
- Do not use exercise to lower blood sugars as this can potentially make the blood sugar go higher.

quick reference guide to blood sugar levels

HOW BLOOD SUGAR LEVELS AFFECT THE STUDENT

low blood sugar < 4

The student may say he/she feels "low", may look unwell, or act in a strange manner

Signs of a low blood sugar include:

- Cold, clammy, sweaty skin
- Paleness, Quietness
- Fatigue, Dizziness
- Shakiness
- Hunger, Irritability
- Tearfulness

Signs of a VERY low blood sugar include:

- Lack of co-ordination
- Hostility
- Confusion
- Staggering gait
- Appearing intoxicated
- Unconscious
- Unresponsive
- Seizure

* the key to keeping a student safe is managing a low blood sugar as soon as it is detected

target range 4 - 10

- Should feel well

high blood sugar >14

- Easily upset
- Dry mouth, Increased thirst
- Tired
- More frequent urge to urinate
- Irritable
- Difficulty concentrating
- Blurry vision

HOW TO SUPPORT THE STUDENT

low blood sugar < 4

- Allow student to check to confirm symptoms
- If student is unable to check, manage as a low blood sugar
- Never leave student alone
- Do not send to office
- Do not allow student to use stairs

Give ONE of the following immediately
175ml (6oz) of juice / pop (not diet) or 3 glucose tablets
or fast acting sugar as directed by parent or 5-6 lifesavers

Follow up as per School Diabetes Plan.

Never give food or drink if student is
Unconscious / Unresponsive / Having a seizure

- Place student on their side
- Call 911
- Be sure to tell EMS the student has type 1 diabetes
- Call the emergency contact

target range 4 - 10

- May need to check blood sugar but otherwise should feel well

high blood sugar > 14

- Allow student to check to confirm symptoms
- Drink water in class
- Unrestricted bathroom privileges
- A high blood sugar is NOT an emergency situation unless the student is vomiting
- Review School Diabetes Plan to see when to contact parent. Student may need insulin to help lower blood sugar

* If the student vomits more than 4 times immediately.
* If you are unable to reach them call 911
* Be sure to tell EMS the student has type 1 Diabetes

elementary students

Helping the young student with diabetes succeed

To protect the young child with diabetes in school, clear and regular communication between the parents and the school is essential. Completing a school diabetes plan is very important.

It is helpful to remember that the young student needs acknowledgement of their normal developmental milestones, in addition to dealing with the challenges of diabetes. Diabetes is part of the child's life however it does not define them. Talking in terms of the child having diabetes rather than being diabetic is helpful because it allows the child to develop the idea that although they have diabetes it does not stop them from being like every other child in their class and participating in all classrooms activities.

It is not uncommon for a student in the younger grades (kindergarten, grade 1, 2) to be unable to recognize the symptoms of a low blood sugar. Similarly, the young student may not be able to effectively communicate when they are feeling unwell. Being attentive to the subtle changes in mood and behaviour can help a teacher identify when a student is experiencing a low blood sugar. This will become easier as the teacher becomes more familiar with the temperament and personality of the student.

A young child will often become quiet and pale with mood changes such as irritability when they are experiencing a low blood sugar. If the student appears to be acting in an uncharacteristic manner and checking the blood sugar is not possible, the teacher should assume that the student is experiencing a low blood sugar and manage the situation as such. A temporary elevation of the blood sugar will not harm the child, but a low blood sugar is potentially serious. Parents should be notified each time their child has a low blood sugar (see the student's school diabetes plan for individual expectations).

It is important to notify parents when supplies of fast acting sugar are becoming depleted.

special concerns
for the young student

Checking blood sugars

The age at which a child is able to perform self care tasks, such as checking their blood sugar is very individual and variable. A child's capabilities and willingness to provide self-care needs to be respected. By age 8, most children can independently perform their own blood sugar checks. The ability to use a meter to check blood sugar levels develops much more quickly than the capacity to interpret the results.

Meal/snack times

Extra supervision may be required during snack or meal time to ensure that the young child eats all of the food provided by the parent. Allowing sufficient time to eat all of the food is important because eating inadequately, delaying a meal or skipping a snack can easily cause a low blood sugar.

If a young child refuses to eat or drink all of their meal or snack a pre-arranged replacement may be substituted, after consultation with the parent, this should be included in the diabetes school plan.

Regular communication between the teacher and the parents regarding special classroom events and changes to the usual schedule will enable the parents to make accommodations and adjustments to the child's diabetes management so they can safely participate in all of these activities.

Allowing sufficient time to eat all of the food is important because eating inadequately, delaying a meal or skipping a snack can easily cause a low blood sugar.

Activity

Exercise can lower blood sugar levels. Young children typically are spontaneous and unpredictable in their activity level. Being prepared and knowing that a low blood sugar can develop at anytime is the key to keeping the student safe.

Playground supervisors should know which student has type 1 diabetes, what the signs and symptoms of a low blood sugar are and the action plan to manage the low blood sugar immediately.

Exercise can lower blood sugar levels.

high school

students

When students enter high school they are expected to assume more responsibility for their learning. This is also a time when they are exposed to new levels of freedom and opportunity.

Students with type 1 diabetes must not only deal with the social and academic challenges of high school, they must also learn to take a more independent role in the management of their diabetes. This independence comes at a time when blood sugars can be particularly difficult to manage, due to the rapid physical growth and psychosocial changes that occur in adolescence.

Teens may be eager to be more independent in their diabetes management, however the consequences of this independence can involve making inexperienced choices with less than perfect outcomes. For teens the challenges of learning to balance freedom and responsibility are compounded by the demands for daily blood sugar management.

There may be times when a teen, with type 1 diabetes, struggles with both the idea of having diabetes and with carrying out the daily tasks of taking insulin, checking blood sugars, and monitoring food and exercise. There is no let-up in this rigorous program nor is there a vacation: therefore, it can happen that teens get tired and frustrated with it.

The teen may struggle with feeling different from their peers and may be reluctant to inform their teachers that they have type 1 diabetes. They may not wish to draw attention to their condition by wearing a medic alert bracelet. They may be embarrassed to check their blood sugar or take their insulin injection at school or around their friends. Caring for their diabetes may become less of a priority for them.

For teens the challenges of learning to balance freedom and responsibility are compounded by the demands for daily blood sugar management.

supporting high school students

Teens don't like to be singled out or made to feel different however anyone with type 1 diabetes, regardless of age, may need help in the event of a low blood sugar. It is important to understand that when a student's blood sugar falls below 4.0 they may not be able to think clearly and they may become easily confused. Hypoglycemia is the greatest immediate danger to any student with diabetes. It can impair cognition and sometimes can be mistaken for misbehavior.

- If a student's behaviour seems out of character ask them to check their blood sugar, if no meter is available assume that they have a low blood sugar and stay with them until they take some fast acting sugar and feel well again.
- If a student misses classroom time or an exam, or if his or her cognition is impacted by lows or highs, give extra time to make up missed work, tests, and other assignments.
- During exams allow the student to eat, drink and check their blood sugar level so they can manage their diabetes accordingly.
- Having an understanding that the student may leave the class to use the bathroom without drawing extra attention to them can be helpful.
- Avoid labeling a teen as being diabetic, they have diabetes, it is a part of who they are but it does not define them.
- Avoid placing value judgments on blood sugar checks or foods that are being eaten. Keeping comments about the blood sugar levels neutral helps the student feel less judged. "Thanks for checking" is a good response.
- Many teens with type 1 diabetes choose to wear an insulin pump to help manage their diabetes. If their pump beeps during class it is important to allow them to call their parent to problem solve issues related to the pump.
- Encourage the student to advocate for themselves by informing all their teachers about their diabetes and their needs in the classroom.
- Encouragement and support from teachers can provide an important safety net for students who try to adjust to all of their new responsibilities. Your understanding can make all the difference in the health and outlook of the student.

helpful tips

1 Every student is unique
Each student with diabetes may have different symptoms of a low blood sugar.

2 Occasional teachers need information.
Make sure all occasional teachers are informed that they have a child, in their classroom, with type 1 diabetes who has a school diabetes plan.

3 Don't draw unnecessary attention to your student's condition
Students with diabetes want to be just like every other student.

4 Don't put a "label" on the student with diabetes
Don't blame diabetes for everything, we all have bad days.

5 Always be prepared
Always carry fast-acting sugar everywhere including recess, fire drills, field trips, special presentations & assembly.

6 Be patient
High & low blood sugars can make it difficult for the student to concentrate, including during tests and exams.

7 Keep the lines of communication open
Regular communication with the student's parents is important. Using the student's agenda to communicate blood sugar readings can be helpful.

8 Consistency
Always inform parents when there will be changes to the daily routine especially if snacks or activity times will be changed.

9 Support Classmates
Make sure classmates understand why the student with diabetes may be eating and drinking in class at times when it is not usually permitted

10 All school staff should know
- Which student has type 1 diabetes
- What a low blood sugar is
- How to respond to a low blood sugar.

physical activity

DIABETES SHOULD NOT STOP A STUDENT FROM ENJOYING ANY KIND OF ACTIVITY. STUDENTS WITH DIABETES SHOULD BE ENCOURAGED TO PARTICIPATE IN AS MANY SCHOOL ACTIVITIES AS THEY CHOOSE. GOOD PLANNING IS ESSENTIAL SO THAT THE BLOOD SUGAR BALANCE IS MAINTAINED. THE MAJOR RISK OF UNPLANNED ACTIVITY IS A LOW BLOOD SUGAR. THIS CAN OFTEN BE PREVENTED BY EATING EXTRA FOOD OR DRINKING A JUICE BOX

- It is critical that all the student's teachers, especially gym teachers and coaches are familiar with the symptoms, management and prevention of low blood sugar reactions.
- If possible, let the student's parents know about upcoming activities so they can plan accommodations for the exercise.
- Ensure the student has their meter and supplies readily accessible whenever they are participating in sports.
- Some students may take a juice box or extra snack before exercising - see school diabetes plan.
- Allow the student to check their blood sugar level whenever they feel unwell and take a fast-acting sugar if the reading is below 4.0.
- Exercise can cause a low blood sugar during an activity, immediately after an activity and up to 24 hours after an activity.

Every student with type 1 diabetes should have a School Diabetes Plan developed in consultation with the student's parents to determine the best support the school can provide to keep the student safe.